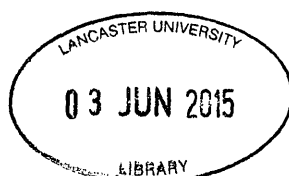


**Facilitation of the Gold Standards Framework
programme for end-of-life care in care homes:
a mixed methods study**

**Julie Kinley (MSc, BSc, RN)
August 2014**

This thesis is submitted in partial fulfilment of the requirements for
the degree of Doctor of Philosophy

Faculty of Health and Medicine
Lancaster University, UK



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Declaration

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Abstract

The implementation of end-of-life care interventions is promoted within English healthcare policy to improve care delivery within different settings. How these interventions are best implemented is less clearly promoted. The role of facilitation in the implementation of one end-of-life care initiative, recommended by the English Department of Health, the Gold Standards Framework in Care Homes (GSFCH) programme is considered in this study. It has been noted that a low number of care homes complete the programme which has raised questions about the implementation process. Whilst an early evaluation reported that it was easier to implement the GSFCH programme when a care home was supported by an external facilitator, this report and subsequent evaluations failed to clearly identify the role or competencies that they needed.

This mixed methods study was undertaken within 38 nursing care homes undertaking the GSFCH programme in England. Qualitative and quantitative data were collected from staff employed within (nursing care home managers and GSFCH coordinators) or associated with (external facilitators) these nursing care homes and included interviews, surveys, Facilitator Activity Logs and a researcher's diary. Following separate quantitative and qualitative data analysis the data sets were integrated by

'following a thread'. Utilisation of a system-based-framework enabled the wider context of the participating nursing care homes to be considered.

Three approaches of facilitation were provided to nursing care home staff when implementing the GSFCH programme: 'fitting it in' facilitation; 'as requested' facilitation; and, 'being present' facilitation. Completion of the GSFCH programme, through to accreditation, was influenced by the approach of facilitation that was provided. Implementation of the programme required an external facilitator who could mediate multi-layered learning at an appreciative system level, an organisational level and at an individual level. Multi-layered learning was required in order to achieve the cultural change necessary to complete the GSFCH programme.

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Support for undertaking this PhD has come from a number of sources. I am very grateful to Dr. Jo Hockley, working as nurse consultant for the Care Home Project Team at St Christopher's Hospice for the majority of this study, for her support and encouragement. She was aware I wanted to eventually work as a nurse consultant and helped me see that this would not be possible without study at doctorate level.

I have been fortunate to have the support of three PhD supervisors. Firstly my thanks go to Dr. Katherine Froggatt who has kept me focused and aware of the expectations of thinking at this level. Many thanks also go to Dr. Mike Bennett and to Dr. Nancy Preston, who took over when Mike went back to Leeds. Both supported me and gave particular encouragement when completing and then re-running my systematic reviews. Thanks also extend to Gareth Ridall, from the department of mathematics and statistics at Lancaster University, for the support I received when integrating the qualitative and quantitative data.

Further thanks go to the participants within this study who generously gave of their time and shared their experiences. I feel very proud to have achieved a 100% data collection and this is down to their enthusiastic participation. Sincere thanks are due to St Christopher's Hospice and Help the Hospices who have encouraged, supported and funded my PhD study, to Ruth Hathaway the volunteer who helped me code the external Facilitators' Activity Log data and to Laing & Buisson who kindly granted permission to use data from the Care of Elderly People UK Market Survey (Laing 2012). My final thanks are to my husband John who has always been there for me despite the long hours devoted to this study.

Contents

Declaration	i
Abstract	ii
Acknowledgements	iv
List of Tables	xv
List of Figures	xviii
List of Boxes	xix
List of abbreviations	xx
Chapter One – An introduction to the study: implementation of end-of-life care policy into practice	1
1.1: Transferring the GSFCH from a national policy recommendation into practice	2
1.2: Why undertake a mixed methods study alongside a Cluster Randomised Controlled Trial	6
1.2.1: Personal reflections.....	7
1.3: Overview of the thesis	9
Chapter Two – Background to the study	14
2.1: Predicted demographic changes	14
2.2: The provision of long-term care to older people internationally	17
2.3: Nursing care homes as a place of long-term care for older people	18
2.4: Provision of institutional care for older people in the UK	18
2.4.1: Historical and current background	19
2.4.2: Nursing and residential care homes as a place to live	24
2.4.3: Demographics of the nursing care home population within the UK	26
2.4.4: Nursing and residential care homes as a place to die	37
2.5: End-of-Life Care	39
2.5.1: End-of-life care (England).....	40
2.5.2: Care homes in relation to end-of-life care	40
2.6: Recommended tools and frameworks for the provision of end-of-life care in care homes	42

2.6.1: The Gold Standards Framework in Care Homes programme (GSFCH)....	42
2.6.2: The Liverpool Care Pathway (LCP).....	46
2.6.3: Education and training.....	48
2.7: Conclusion	49
Chapter Three - Organisational change	51
3.1: Organisations and culture	51
3.1.1: Learning organisations and cultural change	53
3.2: Organisations as systems	54
3.2.1: Systems theory.....	55
3.2.2: Soft Systems Methodology.....	56
3.3: Care homes in relation to organisational change.....	58
3.3.1: Planned or deliberate change, emergent change and spontaneous change.	58
3.4: Context in relation to change	61
3.4.1: Culture and change in care homes	61
3.4.2: Leadership and change in care homes	63
3.4.3: Measurement and change in care homes	67
3.5: Facilitation in relation to change	69
3.5.1: The facilitator’s role and characteristics.....	69
3.5.2: Facilitation styles and purpose	71
3.6: Conclusion	73
Chapter Four – Implementation of end-of-life care interventions: the supportive evidence.....	75
4.1: Evidence of the outcomes from implementing an end-of-life care intervention	76
4.1.1: The research question and aim of the systematic review on outcomes	77
4.1.2: Search strategy.....	77
4.1.3: Results	78

4.2: Evidence supporting the process of implementing an end-of-life care intervention	79
4.2.1: The research question, aim and objectives of the systematic review on process	79
4.2.2: Search strategy.....	80
4.2.3: Data Extraction.....	82
4.2.4: Results:	83
4.2.5: Study design and level of evidence	85
4.2.6: The decision to implement the intervention	86
4.3: Implementation of the interventions	86
4.3.1: Implementation of the GSFCH programme	86
4.3.2: Implementation of the LCP/ICP for the last days of life.....	91
4.3.3: Implementation of education and/or training to support the provision of end-of-life care.....	95
4.4: Study sites	103
4.5: Study participants.....	104
4.6: Change agent	105
4.7: Factors that enabled the intervention to be implemented into practice ..	106
4.7.1: The Preliminary Phase: prior to the intervention commencing.....	110
4.7.2: The Implementation Phase: during the implementation.....	113
4.7.3: The Consolidation Phase: following the implementation.....	115
4.7.4: Role of the nursing care home manager	117
4.7.5: Environmental constraints to consider when implementing an end-of-life care intervention	118
4.8: Discussion.....	119
4.9: Limitations.....	121
4.10: Conclusion	122
Chapter Five - Methodology	124

5.1: Research questions, aim and objectives	124
5.2: Research design	125
5.2.1: Theoretical perspectives	125
5.2.1.1: Mixed methods	126
5.2.2: Epistemology	127
5.2.2.1: This study in relation to epistemology	128
5.2.3: Mixed methods as the research design	129
5.2.3.1: Typologies within mixed methods research design.....	130
5.3: Sampling Strategy	134
5.4: Participants.....	135
5.4.1: Nursing care home manager/s	135
5.4.2: GSFCH coordinator/s	135
5.4.3: External facilitator/s	136
5.4.4: Process of recruitment of the nursing care home managers	136
5.4.5: Process of recruitment of the GSFCH Coordinator/s	137
5.4.6: Process of recruitment of the external Facilitator/s	137
5.5: Methods of data collection.....	138
5.5.1: Interviews	139
5.5.1.1: The rationale for using interviews within this study	139
5.5.1.2: The format of the interview	140
5.5.1.3: How the interview was undertaken	142
5.5.2: Surveys	143
5.5.2.1: The rationale for using surveys within this study.....	144
5.5.2.2: The format of the survey	145
5.5.2.3: Validity, reliability, responsiveness, sensitivity and specificity of the different questionnaires used	146
5.5.2.4: How the survey was undertaken	148

5.5.3: Facilitation Activity Log	149
5.5.3.1: Rationale for use of the Facilitation Activity Log within this study	152
5.5.3.2: The format and use of the Facilitation Activity Log	153
5.5.4: Researcher's diary	153
5.5.4.1: Rationale for use of a researcher's diary within this study.....	154
5.5.4.2: The format of the researcher's diary.....	155
5.5.4.3: How the researcher's diary was undertaken	155
5.6: Methods of analysis.....	156
5.6.1 Quantitative data analysis	156
5.6.2 Qualitative data analysis	158
5.6.3 Integrating data	161
5.7: Rigour and quality	162
5.8: Ethical issues.....	166
5.8.1 Informed consent	166
5.8.2 Confidentiality and anonymity	167
5.9: Conclusion	168
Chapter Six - The participants, their context and the findings from the Preliminary Phase of the GSFCH programme	169
6:1 Study setting and study participants.....	170
6.1.1: The nursing care home managers (M).....	171
6.1.2: The GSFCH coordinators (C).....	172
6.1.3: The external facilitators (F)	172
6.2: Worldview: provision of external facilitation in relation to the nursing care homes external context.....	172
6.3: Environmental Factors: provision of external facilitation in relation to the nursing care homes internal context.....	175
6.3.1: The size of the nursing care home	176
6.3.2: The structure of the nursing care home	179

6.3.2.1: Registration status	179
6.3.2.2: Internal stability.....	180
6.4: Facilitators attributes	180
6.4.1: The external facilitator’s terms of employment	182
6.4.2: The external facilitators’ educational background	183
6.4.3: The external facilitators work experience	184
6.5: The external facilitators’ preparatory work	184
6.5.1: Establishing the external facilitators’ role.....	185
6.5.2: Preparing for the external facilitation role.....	187
6.5.2.1: External facilitators new to the role of facilitation.....	187
6.5.2.2: External facilitators with previous experience of a facilitation role.....	189
6.6: Factors impacting on the Preliminary Phase of the GSFCH Programme	191
6.6.1: Level of preparedness for change in the nursing care home	192
6.6.1.1: The pre-existing level of care provision.....	193
6.6.1.2: Having a culture for engagement with new ventures	195
6.6.1.3: Gaining palliative care knowledge prior to the GSFCH workshops commencing.....	195
6.6.1.4: Creating a support network.....	197
6.6.2: Having a reason to undertake this work	197
6.7: Conclusion	198
Chapter Seven - The Implementation Phase: workshop one to workshop four	199
7.1: The delivery of GSFCH facilitation.....	199
7.2: Approaches to external facilitation	201
7.2.1: ‘Fitting it in’ facilitation	202
7.2.2: ‘As requested’ facilitation	204
7.2.3: ‘Being present’ facilitation.....	204

7.3: The relationship between the different approaches to external facilitation and the delivery of facilitation.....	206
7.3.1: The delivery of ‘fitting it in’ and ‘as requested’ facilitation	210
7.3.2: The delivery of ‘being present’ facilitation	211
7.4: Support from the Regional Training Centre.....	213
7.5: The recorded delivery of facilitation	215
7.6: Factors impacting on the Implementation Phase of the GSFCH programme.....	219
7.6.1: Internal resources.....	221
7.6.1.1: GSFCH coordinators’ motivation.....	221
7.6.1.2: Continuity of GSFCH coordinators.....	224
7.6.1.3: Communication processes agreed and workable.....	224
7.6.1.4: Time to implement action plans	225
7.6.2: Putting systems into place	226
7.6.2.1: Establishing monthly coding meetings.....	226
7.6.2.2: Undertaking reflective practice	233
7.6.2.2.1: Significant Event Analysis (SEA).....	233
7.6.2.2.2: After Death Analysis (ADA).....	234
7.6.2.2.3: Action Learning.....	235
7.6.2.3: Use of specific tools and documentation to guide care	237
7.6.3: Developing internal relationships within the nursing care home	238
7.6.3.1: Visible senior management support and leadership	238
7.6.3.2: Support for the nursing care home manager.....	241
7.6.3.3: Staff that know each other, are valued and work together	241
7.6.3.4: Individual staff groups contributing to the implementation of the GSFCH programme.....	243
7.6.4: Building external partnerships.....	244
7.6.4.1: GP engagement and partnership.....	245

7.6.4.2: Development of partnerships with other professionals	247
7.6.4.3: Local nursing care home support network	249
7.6.4.4: The external facilitator.....	251
7.6.4.4.1: Attending the workshops with the GSFCH coordinators	252
7.6.4.4.2: The external facilitator investing time to establish a relationship with the nursing care home	255
7.6.4.4.3: ‘Being present’ in the nursing care home	256
7.7: Conclusion	257
Chapter Eight - The Consolidation Phase: between workshop four and accreditation	259
8.1: The study participants taking part in the Consolidation Phase	259
8.1.1: The nursing care home managers	259
8.1.2: The GSFCH coordinators	261
8.1.3: The external facilitators	263
8.2: The experience of providing and receiving facilitation during the Consolidation Phase	263
8.3: Factors impacting on the Consolidation Phase - completing and sustaining the GSFCH programme.....	266
8.3.1: Evidence of change.....	267
8.3.1.1: Learning from audit data	267
8.3.1.2: Working towards GSFCH accreditation.....	268
8.3.1.3: Development of the portfolio for GSFCH accreditation	270
8.3.2: A plan to sustain the GSFCH programme in practice	278
8.3.2.1: Individual effort and belief within a team context	279
8.3.2.2: Education	282
8.3.2.3: Having an official programme for sustainability in place	283
8.3.2.4: Establishing links with outside agencies	285
8.4: The role of facilitation after the two year GSFCH programme	287

8.5: Gaps in relation to the GSFCH implementation.....	288
8.6: Vision for a future model of facilitation.....	291
8.7: Conclusion	294
Chapter Nine – Layers of learning when implementing and sustaining the GSFCH programme.....	295
9.1: Individual learning: by the GSFCH coordinators, external facilitators and the nursing care home managers	297
9.2: Organisational Learning	304
9.2.1: Personal mastery	306
9.2.2: Mental models	307
9.2.3: Shared vision	308
9.2.4: Team learning	309
9.2.5: Systems thinking	312
9.3: Systems Learning	314
9.4: Appreciative Learning Systems	316
9.5: My experience of undertaking this study.....	322
9.6: Connecting the findings of the CRCT with the mixed methods study.....	324
9.7: Layers of learning and other change initiatives in care homes	325
9.8: Conclusion	333
Chapter Ten – Conclusion.....	335
10.1: Study findings.....	335
10.1.1: Cultural change required practice based support.....	336
10.1.2: Cultural change needed to be supported by multi-layered learning	336
10.1.3: Cultural change needed all members of a system to take part.....	337
10.2: Strengths and limitations of this study.....	337
10.2.1: Study strengths	337
10.2.2: Limitations of this study	339
10.3: Contribution and recommendations of this study	343

10.3.1: Contribution to knowledge	343
10.3.2: Contribution and recommendations to policy	344
10.3.3: Contribution and recommendations to practice	345
10.4: Recommendations for future research.....	348
10.5: Concluding comment	349
References	350
Appendix One: Palliative Medicine paper reporting the Cluster Randomised Controlled Trial	393
Appendix Two: Palliative Medicine paper reporting the outcome systematic review	405
Appendix Three: PRISMA checklist for the process systematic literature review	418
Appendix Four: External facilitators’ interview schedule.....	420
Appendix Five: Nurse Managers’ Questionnaire	422
Appendix Six: GSFCH Coordinators’ Questionnaire.....	423
Appendix Seven: Summary record of the external Facilitators’ Activity Log... 	428
Appendix Eight: Mind map – mapping ideas during initial reading of external facilitator interviews	429
Appendix Nine: Environmental constraints: mind map and associated template analysis	430
Appendix Ten: Letter confirming ethical approval.....	432

List of Tables

Table 1.1:	Provision of ‘high’ facilitation +/- action learning	5
Table 2.1:	Care home provision in England – Historical Figures (Care Quality Commission 2010a and 2012)	26
Table 2.2:	Nursing care home residents’ demographic details (UK studies)..	28
Table 2.3:	Nursing care home residents: demographics and diagnosis (UK studies).....	30
Table 2.4:	Nursing care home residents’ mortality	35
Table 2.5:	Number of deaths in England of people using adult care services by home type and financial year (Care Quality Commission 2010a and 2012).....	38
Table 4.1:	Inclusion and exclusion criteria	82
Table 4.2:	Format of the GSFCH interventions	88
Table 4.3:	GSFCH interventions.....	89
Table 4.4:	Format of the LCP/ICP interventions.....	93
Table 4.5:	LCP/ICP interventions.....	94
Table 4.6:	Format of the education and/or training interventions to support the provision of end-of-life care	96
Table 4.7:	Education and/or training interventions to support the provision of end-of-life care	97
Table 4.8:	Preliminary Phase – preparation before the intervention’s implementation	107
Table 4.9:	Implementation Phase – requirements during the intervention’s implementation	108
Table 4.10:	Consolidation Phase – requirements following the intervention’s implementation	109
Table 5.1:	Inclusion and exclusion criteria for study participants	136
Table 5.2:	Data collection methods and associated participants.....	139
Table 5.3:	CATWOE mapping to the interview questions.....	141
Table 5.4:	Quality Framework as applied to this study (O’Cathain 2010)...	165
Table 6.1:	Internal context: enabler or barrier to implementing the GSFCH programme.....	177
Table 6.2:	Qualifications of the external facilitators.....	183

Table 6.3:	Past employment of the external facilitators	184
Table 6.4:	Past experience shaping current external facilitation role	190
Table 6.5:	Nursing care homes CSCI rating	193
Table 6.6:	Enablers or barriers when starting the GSFCH programme	194
Table 6.7:	The Macmillan ‘Foundations in Palliative Care in Care Homes’ Training.....	196
Table 7.1:	Receipt of high facilitation by the GSFCH coordinators in the first year	205
Table 7.2:	Descriptions of the external facilitators’ role.....	207
Table 7.3:	Regional Training Centre: advice and support provided to the <i>local facilitation and no local facilitation</i> participants.....	214
Table 7.4:	Regional Training Centre: advice and support provided to the <i>high facilitation and high facilitation and action learning</i> participants	214
Table 7.5:	Total facilitation time provided to the nursing care home	219
Table 7.6:	Internal resources: enablers or barriers to implementing the GSFCH programme	222
Table 7.7:	Putting systems into place: enablers or barriers to implementing the GSFCH programme.....	232
Table 7.8:	Nursing care home managers’ attendance at action learning sets	235
Table 7.9:	Developing internal relationships: enablers or barriers to implementing the GSFCH programme	239
Table 7.10:	Building external partnerships: enablers or barriers to implementing the GSFCH programme	246
Table 7.11:	GP practices with residents in the nursing care home.....	247
Table 7.12:	External facilitators’ attendance at the GSFCH workshops.....	252
Table 7.13:	GSFCH coordinators’ attendance at the GSFCH workshops.....	253
Table 8.1:	Changes in nursing care home manager during the GSFCH programme.....	260
Table 8.2:	Nursing care home manager was a GSFCH coordinator for longer than six months.....	261
Table 8.3:	Nursing care homes with the same GSFCH coordinators at the start and at the end of the study.....	261
Table 8.4:	GSFCH coordinators in post at the end of the study	262

Table 8.5:	Nursing care homes with GSFCH coordinator/s in post at the end of the study who had attended any of the GSFCH workshops	262
Table 8.6:	Receipt of <i>high facilitation</i> by the nursing care home staff in the second year.....	265
Table 8.7:	Enablers or barriers to completing the GSFCH programme	269
Table 8.8:	Logistic regression of the four factors identified as highly significant in relation to successful accreditation.....	273
Table 8.9:	Enablers or barriers to sustaining the GSFCH programme.....	281
Table 8.10:	The external facilitators' vision for a future model of GSFCH facilitation.....	293
Table 9.1:	Median cost of facilitation per nursing care home.....	342

List of Figures

1.1	Relationship of this mixed methods study to the CRCT.....	7
2.1	UK population over 65 years 1901-2081	15
2.2	Nursing and residential care places for elderly, chronically ill and physically disabled, by sector, UK, April 1967-2011.....	21
2.3	Places in all Independent Sector Care Homes (for-profit and not for-profit) for older and physically disabled, UK, April 1967-2011.....	25
2.4	Independent Sector Care Homes (for-profit and not for-profit) for older and physically disabled, UK, April 1967-2011.....	25
4.1	The review process	84
5.1	An overview of the research design.....	132
5.2	The nursing care home sample.....	134
6.1	Nursing care homes and their associated study participants.....	171
6.2	Experience of external facilitation in the Preliminary Phase of the GSFCH programme	182
6.3	Factors impacting on the Preliminary Phase of the GSFCH programme	192
7.1	Year one - total time of facilitation.....	200
7.2	Year two - total time of facilitation.....	201
7.3	Experience of external facilitation of the GSFCH programme.....	202
7.4-7.6	Number of emails, phone calls and visits by the external facilitator to the nursing care home	216
7.7-7.9	Time (hours) of emails, phone calls and visits made by the external facilitator to the nursing care home	217
7.10	Factors impacting on the Implementation phase of the GSFCH programme.....	220
7.11	Facilitation format provided to the local facilitation group.....	228
7.12	Facilitation format provided to the high facilitation group	229
7.13	Facilitation format provided to the high facilitation and action learning group.....	230
7.14	Coding meetings ‘pre’ and ‘post’ GSFCH programme implementation.....	231
8.1	Factors impacting on the Consolidation Phase of the GSFCH programme.....	266
8.2	Accreditation status of the participating nursing care homes.....	271
8.3	Predicted probability of becoming accredited - in relation to hours of accreditation time spent with an external facilitator and number of action learning sets attended	274

8.4	Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended no action learning sets.....	276
8.5	Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended two action learning sets.....	276
8.6	Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended five action learning sets.....	277
8.7	Factors contributing to the implementation of the GSFCH programme.....	290

List of Boxes

Box 6.1:	External facilitators' summary of their role.....	186
Box 7.1:	Action learning as a mechanism of change	236
Box 7.2:	The external facilitator building relationships with staff in the nursing care home.....	255
Box 8.1:	Sustainability of the GSFCH programme: Individual perception of improvement in care.....	280

List of abbreviations

ADA	After Death Analysis
CATWOE	This mnemonic relates to a root definition which includes C ustomer, A ctors, T ransformation, W eltanschauung (or W orldview), O wner and E nvironmental constraints
CRCT	Cluster Randomised Controlled Trial
GSF	The Gold Standards Framework in Primary Care programme
GSFCH	Gold Standards Framework in Care Home programme
ICP	Integrated Care Pathway
HF	<i>High Facilitation</i> - The study group receiving ‘high facilitation’ to implement the GSFCH programme into practice
HF+AL	<i>High Facilitation and Action Learning</i> - The study group whose nursing care home manager received nine months of AL in addition to the nursing care home receiving the ‘high facilitation’
LCP	Liverpool Care Pathway
LF	<i>Local Facilitation</i> - The usual GSFCH facilitation study group that did have an external facilitator
NLF	<i>No Local Facilitation</i> - The usual GSFCH facilitation study group that did not have an external facilitator
OECD countries	O rganization for E conomic C o-operation and D evelopment project - 19 countries (Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, the Netherlands, New Zealand, Norway, Mexico, Poland, Spain, Sweden, Switzerland, the UK and the United States) participated (OECD 2011)
SEA	Significant Event Analysis
SPC	Specialist Palliative Care

Chapter One – An introduction to the study: implementation of end-of-life care policy into practice

Initiatives to guide the delivery of high quality end-of-life care, within all care settings in England, are actively encouraged within the End-of-life Care Strategy (Department of Health 2008). However, this documentation provides little guidance either about the outcomes that could result or how to translate its recommendations into practice. The process by which high quality end-of-life care is implemented has therefore been variable, driven by local interpretation and locally agreed commissioning criteria. Whilst the provision of end-of-life care continues to be driven nationally, how this is achieved within care settings in England consequently varies from one locality to another.

It is now six years since the End-of-life Care Strategy was published. Following its publication, annual reports summarise the progress made on the implementation of its recommendations. However, this annual system of reporting appears to have now ceased with the final assessable report (the fourth annual report) published in 2012 (Department of Health 2012). Evidence of implementation of the recommendations within the strategy was to be through locally agreed measurable outcomes. Core outcome measures suggested in the End-of-Life Care Strategy (2008) included the Views Of Informal Carers – Evaluation Of Services (VOICES), a questionnaire sent to bereaved relatives and through audit of the Liverpool Care Pathway. With respect to the VOICES questionnaire becoming a key outcome measure, this has been delivered on. The fourth annual report includes a summary of the findings from a national survey of bereaved relatives. However, this measurable outcome only relates to the experience of end-of-life care in the last three months of life. The detail of other

outcome measures is not evident. For example the End-of-Life Care Strategy (2008) suggests recording the number of general practices using the GSF or equivalent. This detail for each strategic health authority is provided in the End-of-Life Care Strategy (2008), but not provided in the fourth annual report. In the fourth annual report, instead of reporting this detail for each strategic health authority, a survey of 600 GPs was undertaken. From this survey, 331 GPs reported that they had an end-of-life care register, which is just one component of the GSF primary care foundation level status. Comparison between the reports on this outcome cannot be made.

The decision in 2014 to withdraw one of the End-of-Life Care Strategy (2008) recommendations, the Liverpool Care Pathway, from clinical practice is discussed later, but highlights the importance of reviewing the recommendations and outcome measures within the document in light of the current landscape. This study aimed to examine one other specific end-of-life care initiative recommended by the End-of-life Care Strategy (Department of Health 2008) – the Gold Standards Framework in Care Homes (GSFCH) programme. The primary aim of the study was to identify the role of facilitation when implementing the GSFCH within nursing care home practice.

1.1: Transferring the GSFCH from a national policy recommendation into practice

Support from an external facilitator to care homes implementing the GSFCH programme is recommended by those who developed the programme (Thomas et al 2005) and by those who have evaluated it (Clifford et al 2007). However, it has never been a pre-requisite to a care home starting the GSFCH programme.

With respect to this recommendation, the GSF Central Team highlight core responsibilities of an external facilitator within their training manual for the GSFCH programme (Gold Standards Framework Centre CIC 2011). This document recommends that care homes should have access to an external local facilitator who will:

- have a working knowledge of the GSFCH programme
- have access to electronic versions of all the resources the care home need for the preparation stage (letters etc)
- help review the After Death Analysis (ADA) audits
- arrange and attend GSFCH coordinator supportive meetings
- where possible, attend four GSFCH workshops
- establish a good working relationship with the care home staff

Badger et al (2009), making reference to the external facilitator role, suggests that an additional role is that of assisting the manager of the care home to access additional training external to the home. However, external facilitators are not employed by the GSF central team and so they have been unable to enforce a model of best practice with regards to the use of external facilitators in care homes. As a consequence of this, very little is known about facilitation of the GSFCH programme; and, where local facilitation is provided, different approaches exist.

Despite acknowledging the role of an external facilitator as important, there is little evidence about how such facilitation of the programme should be provided and no evidence of outcomes that result from its provision. Even so, the GSFCH programme continues to be encouraged as a national end-of-life care policy.

Historically, care homes participating in the central GSFCH programme have not always completed the programme. Completion occurs when the care home becomes accredited. The 2012 accreditation database lists 328 care homes who have been accredited (GSF Centre 2012). With over 2,500 care homes having undertaken the programme, the national average of those gaining accreditation is no greater than 13% (Thomas 2012). The low number of care homes completing the GSFCH programme raises questions about its implementation.

In 2008, the GSF central team commissioned a Regional Training Centre to organise and provide a yearly GSFCH programme. As there was no formal model to guide the provision of local GSFCH facilitation, this provided an ideal opportunity for research in relation to the facilitation process. The Regional Training Centre was intending to utilise a high facilitation model following recommendations made from a small study undertaken in Scotland (Hockley et al 2010). A new Care Home Project Team was established at the Regional Training Centre to specifically provide facilitators for the GSFCH programme. With no strong scientific evidence supporting a model of facilitation and how the programme was best to be implemented and sustained gave an opportunity for research. I was employed to undertake this research. After deliberation and a literature review it was decided to undertake a Cluster Randomised Controlled Trial (CRCT) which hypothesised:

When implementing the Gold Standards Framework in Care Homes (GSFCH) programme, action learning alongside a level of high facilitation will result in a reduced proportion of deaths in hospital for residents and improvement in the ability of the care home staff to facilitate good end-of-life care.

There were two approaches to facilitation that were compared in the CRCT *high facilitation (HF)* and *high facilitation and action learning (HF+AL)*. Within both groups a structured approach of high GSFCH facilitation was constructed and agreed (Table 1.1). In the *high facilitation and action learning* group the structured approach of high facilitation was provided, but with the addition of action learning sets, for the nursing care home managers (Table 1.1). There were twelve nursing care homes randomised into each group.

Table 1.1: Provision of ‘high’ facilitation +/- action learning

GSFCH	Provision of high facilitation
During the Preliminary Phase (June 2009-August 2009)	<ul style="list-style-type: none"> • The appointment of two GSFCH coordinators from each nursing care home (large nursing care homes were encouraged to appoint an additional GSFCH coordinator) • Macmillan ‘Foundations in Palliative Care for Care Homes’ (Macmillan Cancer Relief 2011) training for all GSFCH coordinators
During the Implementation Phase (the first year) (September 2009-May 2010)	<ul style="list-style-type: none"> • External facilitator to visit nursing care home 2-3 times a month (+/- one contact) • Training of 80% of the nursing care home staff in how to use the Liverpool Care Pathway/Integrated Care Pathway or minimum protocol and helping them to implement this
Provision of action learning – for those in the high facilitation and action learning group	
Action learning was provided alongside high facilitation as described above. In this group each nursing care home manager was asked to attend a three hour action learning group every month for nine months. The action learning sets were facilitated and took place between the first and fourth GSFCH workshops.	
During the Consolidation Phase (the second year) (June 2010-May 2011)	External facilitator support in the development of local nursing care home network forums which provided: <ul style="list-style-type: none"> • Induction days for all new staff every 6 months • Macmillan ‘Foundations in Palliative Care for Care Homes’ training - four modules per year for carers and nurses • Role modelling for complex situations by Clinical Nurse Specialist/external facilitator

A third group (n=14) of nursing care homes had paid to undertake the GSFCH programme but were located out of the immediate Regional Training Centre area. This group received external facilitation according to what was available and/or funded in

their individual localities. The CRCT measured identified outcomes arising from the implementation of the GSFCH programme in relation to the provision of each of these three approaches to facilitation. The CRCT was completed and the results published ahead of the submission of this thesis (Kinley et al 2014). A copy of the published paper is provided in Appendix One. The findings of the CRCT are considered in relation to this study in chapter nine.

1.2: Why undertake a mixed methods study alongside a Cluster Randomised Controlled Trial

This mixed methods study was undertaken to consider the process of facilitating the GSFCH programme. The study commenced in 2010 independent from, but embedded within the CRCT. The intellectual property for this study is separate from that of the CRCT. Whilst the CRCT gave information on the outcomes linked to varying levels of provision of facilitation, it did not give information on how these approaches to facilitation impacted on those providing and those receiving facilitation. Whilst, one of the three approaches to facilitation might have been more effective than the others, the approach may not have been acceptable to either those implementing it or receiving it. The focus of the PhD would provide this perspective. Figure 1.1 shows the relationship between these two separate studies.

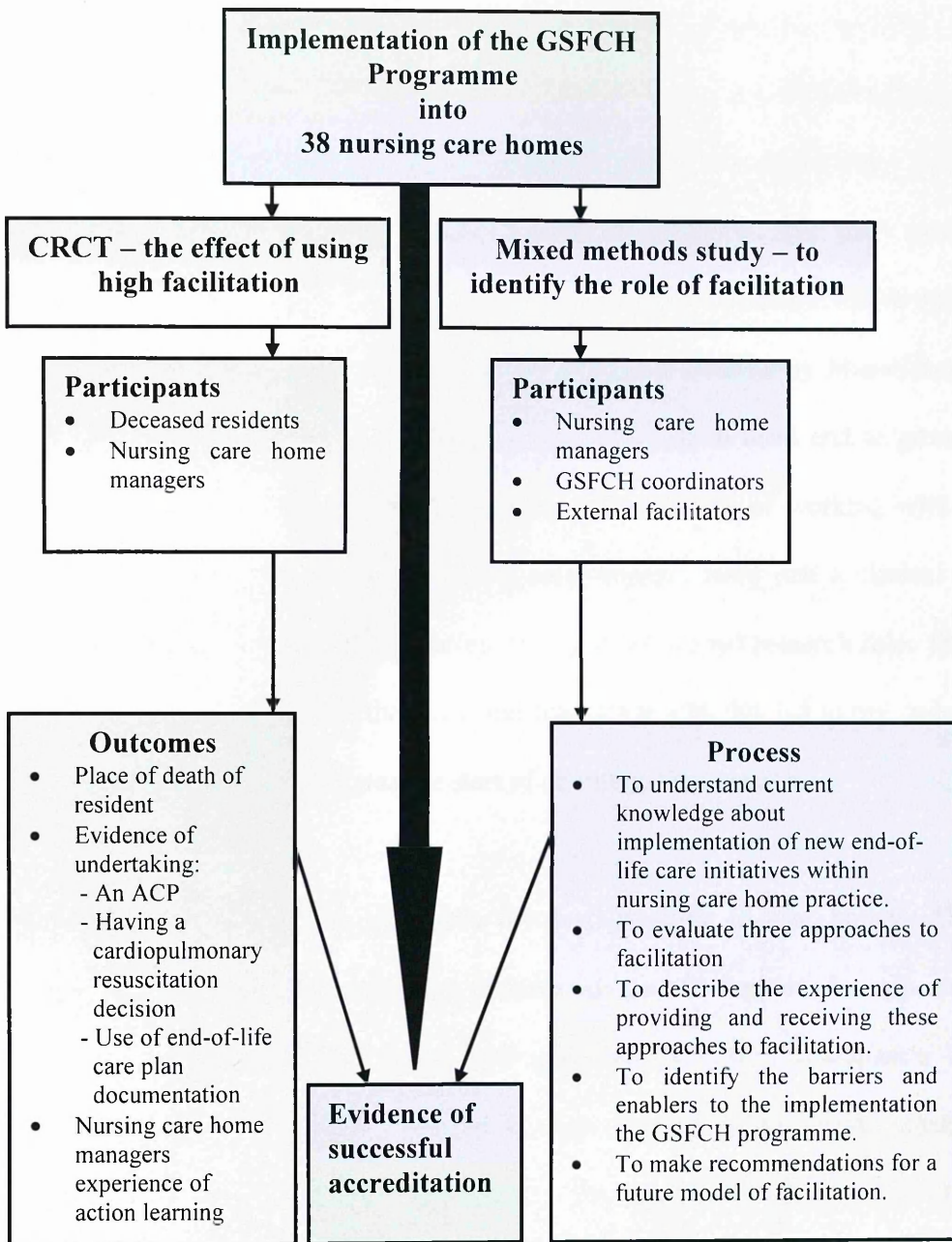


Figure 1.1: Relationship of this mixed methods study to the CRCT

1.2.1: Personal reflections

This study was undertaken a year after I started work at St Christopher’s Hospice in the Care Home Project Team. Prior to this my career had been almost entirely within specialist palliative care (SPC).

After completing my Registered General Nurse training I began my working career in a mixed speciality ward. Three beds were allocated for the care of HIV patients and as this was in the 1980s their care was palliative in nature. The opportunity to develop meaningful relationships with these patients at this time in their lives gave me a passion for palliative care which has persisted throughout my career. I have spent over twenty years working in SPC mainly in the role as a community Macmillan nurse. Over this time the role changed substantially, according to need and to government direction. The SPC role with cancer patients altered to one of working with people with life limiting disease. Over time the role changed from just a clinical role to include education and, in theory, incorporating an additional research role. Time and resource pressures prevented the latter and frustration with this led to my undertaking an MSc independently. This was the start of an interest in research.

My community Macmillan nurse role involved working in care homes. This was mostly in nursing care homes giving reactive advice and support. An opportunity to undertake a research study in this field arose in 2009. St Christopher's Hospice obtained funding to undertake a research study looking at the implementation and sustainability of the GSFCH programme. The study was intended to measure outcomes of different models of facilitation of the GSFCH programme but did not take account of process and experience of facilitation. This became the focus of my thesis as I came to realise that understanding the process of change is as important as measuring the outcomes from change.

1.3: Overview of the thesis

This thesis is divided into ten chapters. A brief resume of the contents of each of the remaining nine chapters is now provided as an introduction to the whole.

Chapter Two: Background to the study

Within this chapter the global increase in the older population is acknowledged. The impact of this is considered in relation to the provision of care for frail older people internationally and then specifically in relation to care provision within the UK. It is recognised that the change in population demographics has, and will continue to have, an impact on care provision.

Within the UK, the provision of long-term care for older people within nursing and residential care homes is increasing (Laing 2012). The place of nursing care homes as a location for health and social care for older people is described, and the relationship between care for living and dying people considered. The demographic changes mean that nursing care homes within the UK are now providing end-of-life care for their residents. End-of-life care is defined. With the recognition that nursing care homes need to provide end-of-life care (Department of Health 2008), recommendations as to how this may be achieved have been produced. The specific end-of-life care tools they recommend, including the GSFCH programme, are described.

Chapter Three: Organisational change

The role of care homes as health and social care providers in the UK has changed. Caring for residents living in a care home is not new. What is new is caring for the increasing numbers of residents dying in a care home. In order for care home staff to

deliver appropriate care provision for their residents, organisational change is required.

The theory of organisational change is considered. Soft Systems Methodology is drawn on and forms the conceptual framework for this thesis. It enables mapping an understanding of what a complex organisational unit is doing, allowing its users to gradually develop a more comprehensive understanding of the situation under study. A rationale for this approach is offered. The source and format of change within an organisation are also considered (Iles 2006).

Kitson et al's (1998) work is drawn upon, to look at how new knowledge is implemented in practice. They propose that the context where the change is occurring, the quality and the nature of the evidence being used to underpin the change (see chapter four) and the process by which it is facilitated need to be considered. The care home context in relation to organisational change is described. The remainder of this chapter looks at facilitation in relation to organisational change.

Chapter Four: Implementation of end-of-life care interventions: the supportive evidence

The evidence is offered from two systematic reviews. The first review reports on measurable outcomes following the implementation of either the Liverpool Care Pathway (LCP)/Integrated Care Pathway (ICP) for the last days of life, the GSFCH programme and education and/or training interventions used to support the provision of end-of-life care (Kinley et al 2013a). The focus of the second review was to identify the factors that enabled and hindered the integration of the three interventions into nursing care home practice and to identify evidence where sustainability of the

intervention had been considered. The findings of these reviews are explored in relation to this study and give an understanding of both the outcome of the Department of Health (2008) drive to promote quality end-of-life care and the process by which this has been achieved in nursing care homes.

Chapter Five: Methodology

The study adopts a mixed methods design. The background to mixed methods is given. The decision to undertake a mixed methods study was as a consequence of three factors: the complex nature of the intervention; ensuring fidelity; and, enabling complementarity. The qualitative and quantitative data that was collected investigates different aspects of facilitation and the integration of the findings, by ‘following a thread’ (Moran-Ellis et al 2010) enabled broader interpretations and conclusions to be drawn from the study. Details are provided on the study participants, data collection methods, analysis, rigour and quality and ethical issues.

Chapter Six/Seven/Eight: The role of facilitation throughout the GSFCH programme

These three chapters report the results of the mixed methods study. The GSFCH programme consists of three phases (Preliminary, Implementation and Consolidation) and the results are reported in relation to these three phases:

- **Chapter six** reports the results from the GSFCH Preliminary Phase. The wider nursing care home context, referred to as the ‘worldview’ and the specific nursing care home context, referred to as ‘environmental factors’ are considered. The preparatory work undertaken by the external facilitators and the nursing care homes, before the GSFCH workshops started, is identified.

- **Chapter seven** reports the results from the GSFCH Implementation Phase, when the nursing care home staff attended four workshops each lasting a whole day. The approaches used when delivering facilitation are identified. The experience of the external facilitators using these approaches, alongside the experiences of the nursing care home staff in receiving the facilitation associated with each approach, is described. Factors that participants identified that enabled the implementation or acted as barriers to the Implementation Phase of the GSFCH programme into practice, are reported.
- **Chapter eight** reports the results from the GSFCH Consolidation Phase, where staff were embedding into practice what they had learnt and working towards accreditation of the programme. A vision for the future approach to facilitation of the GSFCH programme is provided based on the experiences of the external facilitators.

Chapter Nine: Layers of learning when implementing and sustaining the GSFCH programme

Within this chapter the findings of the study are interpreted and discussed. The Soft Systems approach that this study took ensured the implementation of the GSFCH programme into practice was considered from both the perspective of those providing, as well as those receiving, facilitation from the beginning of the programme (Preliminary Phase) through to its completion (Consolidation Phase). The use of a mixed methods study design enabled a greater understanding of the process of facilitation within this programme.

The need for cultural change when implementing the GSFCH programme is highlighted. From the system wide perspective that this study took a model of multi-layered learning to achieve this is proposed. Finally my experience of undertaking this study is considered.

Chapter Ten: Conclusion

A summary of the findings from the study are given. The strengths and limitations of this study are considered, its contribution to knowledge and policy, and practice recommendations are given. This was particularly important as it was always intended that the findings that emerged from this PhD would be relevant to practice. They would provide recommendations about a model of facilitation for the sustainable implementation of the GSFCH programme with a better facilitation process for nursing care home GSFCH coordinators, nursing care home managers and external facilitators who attend future programmes. Finally recommendations for future research are highlighted.

Chapter Two – Background to the study

The predicted changes across global, European, UK and English populations have implications for the nature of care that older people receive and the place of care, as they age. The consequences of these changes are discussed. A more detailed discussion in relation to the provision of care for older people in nursing care homes in the UK follows. This discussion incorporates information from a literature review. The literature review was undertaken to identify the specific demographic details and diagnoses of residents who are living in nursing care homes and dying in nursing care homes in the UK. The population changes were deliberately considered, alongside the literature review, to gain an understanding of the applicability of implementing models of care, particularly end-of-life care, in nursing care homes.

2.1: Predicted demographic changes

The global population is both aging and increasing (World Health Organisation 2012). From 2010 to 2050 the number of people aged 60 and over is predicted to increase from 894 million to 2.43 billion (Rutherford 2012). Proportionally, this means 22% of the global population will be 60 years or over by 2050. The predicted expansion in numbers of older people is greatest in developed societies, but varies country to country: in America, 21% of the population will be 65 or over by 2050 compared with 36% in Japan (Rutherford 2012). These predictions are similar to those expected in the 27 members of the European Union. The greatest increase is predicted in those people aged 80 years and above, rising from 23.7 million in 2010 to 62.4 million in 2060 (European Commission 2012). The prevalence of frailty is known to increase with age (Age UK 2013), and so an increasing aging global population will potentially

lead to increased demands for health and social care. Of note, is the rise in dementia with the level predicted to double every 20 years (World Health Organisation 2012).

Using the UK as a specific example, Rutherford (2012) report an 80% increase in the number of people living within the UK, aged 65 and over in the last 60 years. The greatest change is in the population over 85 years; and, from 1951-2012, their numbers have increased from 4% to 14% of the total UK population. This demographic change is predicted to continue, so, by 2081, the UK population aged over 85 may increase to 7.8 million from 1.45 million in 2011 (Laing 2012). The previous, current and predicted UK population change can be seen in Figure 2.1.

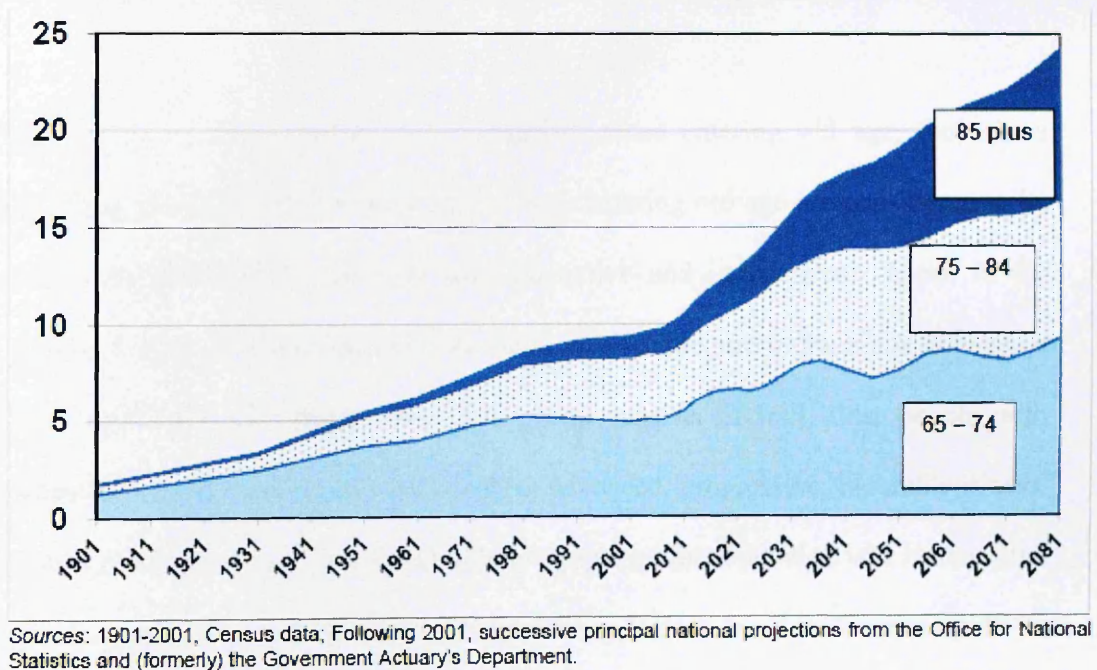


Figure 2.1: UK population over 65 years 1901-2081 (Laing 2012)

Over time, the demographics of the UK population have substantially changed in relation to age and cause of death. In 1900, those dying were often young and a large proportion of these deaths were from acute infections (Hicks and Allen 1999). The

causes of death have shifted from acute life-threatening infectious diseases in the young (Hicks and Allen 1999) to chronic medical conditions (World Health Organisation 2004). In the UK, in 2010 36% of the 1.4 million people in the population aged 85 or older died (Calanzani et al 2013). Calanzani et al (2013) predict that in 2035 half of all UK deaths will be in the predicted 3.5 million population aged 85 or older. As the UK population becomes older, organisations providing care will need to be able to adapt to meet their needs. In an attempt to guide organisations to do just this, the Department of Health (2001) developed the National Service Framework for Older People. The intent of the document was to create a strategy that would enable fair, high quality, integrated health and social care services for older people. The emphasis was on supporting independence and promoting good health.

Three groups of older people were identified: those entering old age, those in a transitional phase and frail older people. Those entering old age are considered to be between the sixth and seventh decade and active and independent. Those in the transitional phase, between the seventh and eighth decade, are in transition between a healthy active life and frailty. The third group consists of frail older people with considerable health and social needs such as advanced, progressive, incurable illness. It is likely that the proportion of frail elderly people in the population will increase the most, based on current aging trends. The provision of care, in all its locations, will be shaped by these population changes.

Eighty percent of all deaths occur in people aged 65 years or older, usually from serious chronic diseases (Costantini and Lunder 2012). All countries will need to consider how they meet the increasing need for care for this population both living

and dying. Those aged over 85, known as the ‘oldest old’ (Age UK 2013), with the greatest dependency (such as with multiple co-morbidity and dementia) may require institutional care until death.

Internationally, Broad et al (2013) report that across 21 global populations, 18% (median) of older people died in residential aged care. They reported that the age group most associated with the risk of dying in such institutions was at its highest for those 85 or more. One option may be, as Abbey et al (2006:56) stated, nursing care homes become ‘hospices of the future’. It would seem from these figures that, internationally, such institutions are already providing this role. This role is likely to increase given the expected population changes, unless new models of care emerge. The next section illustrates this with an exploration of long-term care provision and care homes, as a place of care for older people.

2.2: The provision of long-term care to older people internationally

Long-term care is defined as ‘care for people needing daily living support over a prolonged period of time’ (OECD 2011:38). Such care may be provided within institutions (the term used varies internationally) or within an individual’s own home. Across OECD (Organization for Economic Co-operation and Development project) countries (see glossary) 2.3% of the population uses long-term care services but there is great variety from 5.1% of the population in Austria to 0.2% in Poland. Half of all users are over 80 years (OECD 2011). The current and predicted population changes, described earlier, raise issues of both funding long-term care and managing service provision. Both have resulted in international interest (OECD 2011 and Froggatt and

Reitinger 2013). The focus in this thesis is nursing care homes as they provide care for those with the greatest dependency (Meijer et al 2000).

2.3: Nursing care homes as a place of long-term care for older people

The use of nursing care homes for long-term care firstly depends upon their availability. In Belgium, for example, until 1980 there were no nursing care home facilities and even then nursing care home beds could only be created to replace acute hospital beds that were closed (Meijer et al 2000). Meijer et al (2000) looked in detail at service provision for the increasing numbers of the frail elderly population in the Netherlands, Germany, Denmark and Belgium. They concluded that the four countries were responding by controlling the use of nursing care home services. This included looking for alternative forms of care, applying selective admission criteria and funding i.e. pressuring nursing care homes to operate for lower costs (Meijer et al 2000). With the prediction that the numbers of older people will continue to increase there will be a need for health and social care provision to continue to adapt. The next section illustrates the emergence of long-term care institutions and nursing care homes, as a place of care for older people in the UK.

2.4: Provision of institutional care for older people in the UK

In the UK, care homes provide accommodation, together with nursing and personal care (subsequently referred to as nursing care homes) or only personal care (subsequently referred to as residential care homes) (Department of Health 2000).

2.4.1: Historical and current background

Historically, institutionalised care for older people, within the UK, has been provided since 1834 (Katz and Peace 2003 and Davies and Seymour 2002). The Poor Law in 1834 created a legal responsibility for society to provide care for those who were without employment, money or shelter or were sick and without family support. This significant change in community responsibility led to the development of many voluntary hospitals and workhouses. As voluntary hospitals provided care only for those individuals with financial resources, care for the majority in need was provided within workhouses. Whilst half the population in workhouses was elderly, qualification for a place was based on need not age.

In 1880, a Smallpox epidemic led to a demand for institutionalised nursing care, from individuals who wanted to and could afford to pay for such care. However, care provision was of a poor standard and unregulated until 1927 with the introduction of the Nursing Homes Registration Act.

In 1920, workhouse institutions changed to Public Assistance Institutions and care for their growing population came under the supervision of borough councils. Care provision for older people was basic: 'The elderly were accustomed to ill health without anticipation of humane or effective care. Their health was poor and their expectations low' (Webster 1991: 168). This system continued until results from the 1947 Nuffield Survey of Public Assistance Institutions led to the 1948 National Assistance Act, recommending the replacement of these large scale institutions with small 25-30 bedded residential institutions. The Act also recommended that care be divided between those requiring nursing and those requiring care and supervision. The

Public Assistance Institutions were divided: some became hospitals, some went to local authorities as residential homes and some became joint establishments. Thus, care of older people with minimal health care needs or who primarily needed social care was provided by local authorities within old people's homes (often referred to as residential or part III homes). Provision for older people with more complex care/health needs was met in nursing care homes or long stay geriatric and mental health hospitals (Laing 2012).

No assessment of need for nursing or residential care was required until it was introduced with the 1990 Community Care reforms (Griffiths 1988). Griffiths (1988) was asked to review the way public funds were used to support the current community care policy. He found that for individuals requiring long-term care, it was 'a matter of chance' where they received this. Three possible options were a residential care home, a nursing care home or a geriatric ward. All of these had a variety of costs and charges. Alongside this, was a review of how to safely close large mental health hospitals. Griffiths' (1988) conclusion was that local social services should assess each person's need for long-term care and undertake a financial assessment. Griffiths (1988) also advised that all care homes, regardless of type and size, should be subject to the same regime of regulation and inspection by social services. In addition, each care home was required to publish a statement of the services it provided. The care home would then be registered in relation to this statement; registration and inspection should ensure adequate staffing. In 2002, with the aim of care provision being based on residents needs, not on registration, the distinction between nursing and residential care homes was removed. Care homes were defined as providing accommodation, together with nursing or personal care (Department of Health 2000).

As the NHS withdrew from the provision of long-term care, there was a major expansion of care provision within the private and voluntary sector. In the UK, care that was once traditionally provided within the public sector has now been transferred to the predominantly private sector (Figure 2.2).

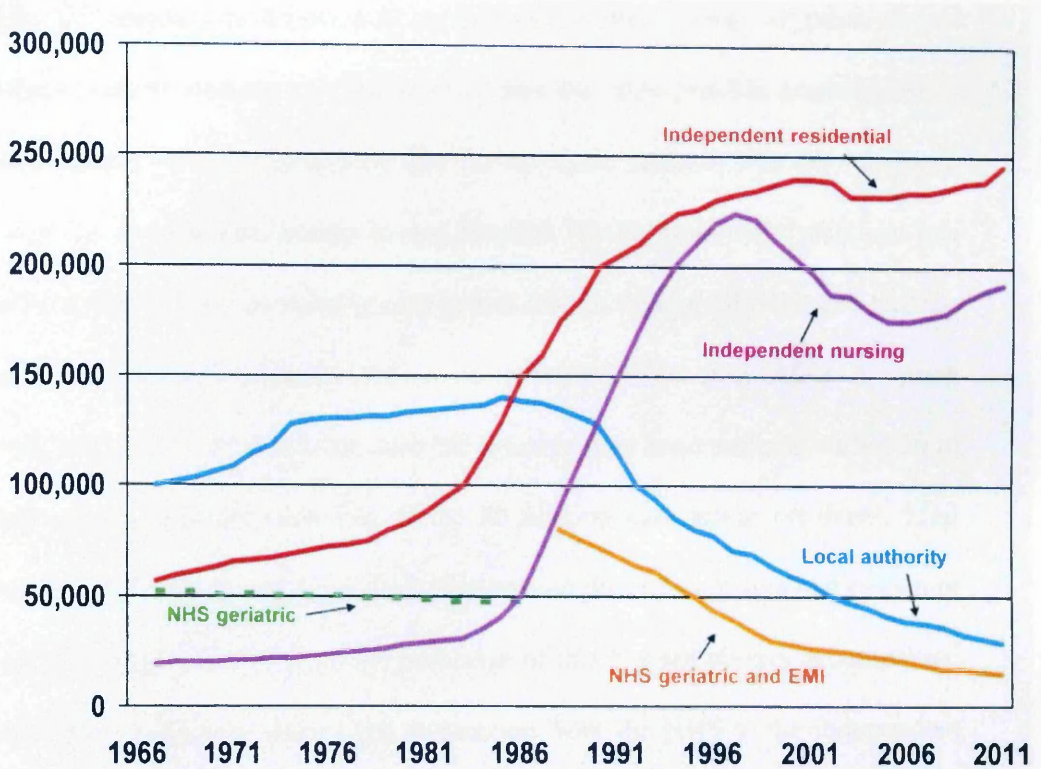


Figure 2.2: Nursing and residential care places for elderly, chronically ill and physically disabled, by sector, UK, April 1967-2011 (Laing 2012)

Over half of all beds allocated for health care in the UK are in independent nursing care homes for older people (Kerrison and Pollock 2001a). In England, the nursing home industry grew dramatically from 28,000 places in 1983 to 196,000 in 1999, whilst the number of NHS beds declined from around 400,000 in 1974 to 190,000 in 2000 (Kerrison and Pollock 2001b).

Some of the difficulties for nursing care homes may arise from the transition of chronically sick older peoples' care from care of the elderly wards to nursing care

homes. The transfer of medical care from geriatric consultants to GPs has not always been accompanied by a transfer of resources and skills (Bowman et al 2001). Collaboration between nursing care home staff and GP practices is paramount. However, there is considerable variation in the medical management of older people provided by GP practices to residents in nursing care homes. Some GP practices are paid 'retainer' fees by nursing care home providers and may provide greater clinical advice and support than GP practices that do not have retainer fees. A telephone survey of all 51 nursing care homes in one English Health Authority (response rate 96%) revealed that 20% of the nursing care homes had no regular GP visit and half the nursing care homes had no planned medication reviews (O'Dea et al 2000). A survey by Bowman et al (2001) revealed that each GP practice may have patients within 10 to 20 nursing care homes and each GP, 20 to 30 nursing care home residents. Frail elderly people are living in nursing care homes and so provision of medical care here is essential. However it would seem the provision of this has not always accompanied the transfer of the long-term care of this population from the NHS to the independent sector (British Geriatric Society 2011). Bowman et al (2001) concluded that if demand on acute hospital services from nursing care home admissions is to be reduced then geriatric medicine needs new investment 'beyond the hospital walls' (Bowman et al 2001:42). A recent publication by Kinley et al (2013b) detailing the support provided by external healthcare providers to residents in their last six months of life supports this notion. O'Dea et al (2000) concluded that the government has a responsibility to ensure that healthcare is provided and that this provision should not be at the discretion of the health authorities and home owners.

Care home provision and ownership varies. The majority of care homes are run for profit and consist of large chains, rather than sole ownership homes. As a result there is pressure on making a profit, with budgets to meet and very limited resources. Members of staff receive little more than the national minimum wage (Laing 2012). In addition to minimal wages there are no specific standards to guide staffing ratios in care homes. Staffing levels are set instead according to the discretion of management 'it is the responsibility of providers to ensure that their staffing is adequate, with the necessary qualifications, skills, and experience' (Laing 2012:79 and Care Quality Commission (2013a). In 2011, there were 4,371 for-profit and 520 non-profit nursing care homes (Laing 2012). Laing (2012) reported that the number of 'major providers' operating these services (defined as including three or more care homes) increased from 34.5% in April 2004 to 57% in April 2011. The NHS role is now as a purchaser of long-term care from this private sector, for those older people meeting specified criteria rather than as a direct provider of care.

The future provision of care within this sector may yet change again. In England, recent reports have highlighted concerns about, and make recommendations to improve, the provision and funding of care for older people (Barker 2014; NHS England 2014; and Burstow 2014). The Burstow (2014) report highlighted the increasing frailty of residents living in residential care homes as well as in nursing care homes in England. Responding to this are a number of recommendations, made within this report, that have the potential to revolutionise the provision for those needing health and/or social care. This includes a recommendation that the terms 'nursing care home', 'residential care home' and 'extra care housing' come under one umbrella to be re named 'housing with care'. The Barker report (2014) recommends

the realignment of care provision so that equal support for equal need is provided regardless of the need being health or social related. Although this report recommends integration, its focus is actually on entitlement and funding. Options for the funding of health as well as social care are presented. Following consultation, the final report recommendations will influence provision and the cost of care to individuals. This may in turn influence the place of care. Whilst provision of integrated care is promoted, the report's focus is on generating funding to achieve this. Within the new system recommended within the Burstow (2014) report, cost would be delineated into rent, service charges and care costs. It seems cost is being segregated just as service provision (Barker 2014) is being integrated.

2.4.2: Nursing and residential care homes as a place to live

In relation to those living in care homes Laing (2012) reported that in April 2011 in the UK:

- In the population, of people aged 65-74 years, 0.7% were living in a long stay hospital setting or a care home
- In the population, of people aged 85 years and over, 15.8% were living in a long stay hospital setting or a care home

The increasing number of older people in the UK has impacted on the provision of long-term care. Overall, the numbers of places across all independent care home services providing care for older and physically disabled people have increased (Figure 2.3). From 2005-2011 residential care home services decreased; although there has been a small, but steady rise, in the number of nursing care home services since 2007 (Figure 2.4), the fall in residential care home services has been larger.

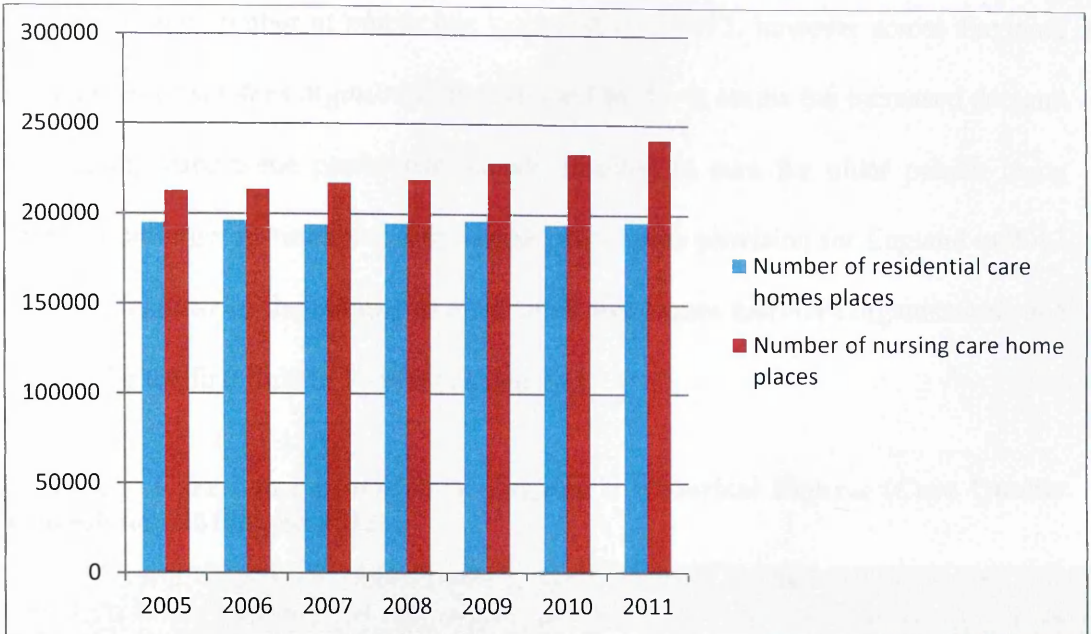


Figure 2.3: Places in all Independent Sector Care Homes (for-profit and not for-profit) for older and physically disabled, UK, April 1967-2011 (Laing 2012)

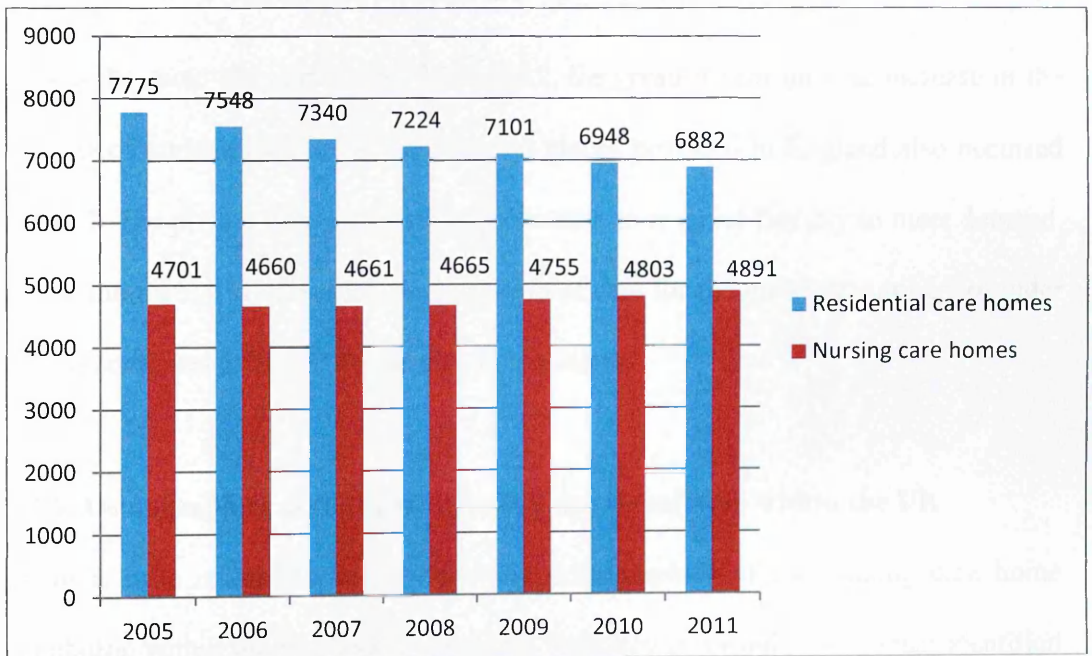


Figure 2.4: Independent Sector Care Homes (for-profit and not for-profit) for older and physically disabled, UK, April 1967-2011 (Laing 2012)

A similar pattern is reflected in the number of residential and nursing care home services and places in England. In relation to nursing care homes from 2003-2009

(Table 2.1) the number of *places* has increased by 11,973, however across England, the number of *services/organisations* decreased by 48. It seems the increased demand for nursing care home places has already resulted in care for older people being provided in larger institutions. Surprisingly, care home provision for England in 2012 show an increase in the number of residential care homes (services/organisations and places) for the first time in 10 years (Table 2.1).

Table 2.1: Care home provision in England – Historical Figures (Care Quality Commission 2010a and 2012)

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Residential care homes	services	services	services	services	services	services	services	services	services	services
	15,632	15,492	15,089	14,812	14,572	14,365	14,123	13,903	12,794	13,134
Nursing care homes	places	places	places	places	places	places	places	places	places	places
	255,959	275,741	271,788	268,442	265,539	262,633	260,488	256,794	234,584	247,878
Residential care homes	services	services	services	services	services	services	services	services	services	services
	4,281	4,141	4,108	4,123	4,119	4,153	4,233	4,352	4,458	4,674
Nursing care homes	places	places	services	places	places	places	places	places	places	places
	180,708	178,507	179,246	181,797	182,920	185,116	192,681	202,654	202,040	215,524

Across the same ten year period, 2003-2012, the greatest year on year increase in the number of nursing care home services and places provided in England also occurred in 2012. The private care sector seems to be able to respond flexibly to meet demand. At the moment, it would seem, the provision of care for the growing numbers of older people continues to be met by the care home sector.

2.4.3: Demographics of the nursing care home population within the UK

There is little research that identifies the demographics of the nursing care home population within the UK. Information was therefore extracted from papers identified in a systematic literature search that was undertaken in April 2013 (see chapter four). Since the systematic literature review, information from additional, relevant published papers identified through personal reading and suggestions from colleagues have been incorporated.

The literature review identified 15 UK studies. Two additional papers Kinley et al (2013b) and Stewart et al (2014) were subsequently identified and are included. Table 2.2 provides an overall summary of these studies in relation to the date of data collection, the study design, location, population and methodology.

The studies use data that was collected between 1991 (Mathews and Dening 2002) and 2012 (Stewart et al 2014). Where details were provided, the nursing care home sample varied from 126 to 11,575 residents (Table 2.2). The study design, and methods also varied, with some data being collected from residents on admission (Bowman et al 2004) and others, after a death had occurred (Hockley et al 2008). This affected the demographic summary the authors provided of the residents, as presented in Table 2.3. The effect of this is illustrated by Dale et al (2001) who provided data on the age of residents on admission (males 75 years and females 80 years) and at death (males 81 years and females 84 years).

Table 2.2: Nursing care home residents' demographic details (UK studies)

Reference	Data collection date	Study design	Study location	Sample		Study method
				Total study sample	Nursing care home sample	
Mathews and Denning (2002)	1991-1993	Multi-centre population based longitudinal study	Occurring in five centres across England and Wales	13,004	189	Interview in care home using listed assessment tools.
Raines and Wight (2002)	1993-1997	Retrospective cohort	Wakefield nursing care homes	841	841	Survival analysis of local authority funded long-stay residents admitted to a nursing care home – divided into year cohorts.
Dale et al (2001)	1994-1995	Retrospective case note audit	Manchester Health Authority	59 nursing care homes with bed provision of 2,115	1,556 residents	When deaths occurred their admission details were sex matched with a current living resident living in the nursing care home.
Bebbington et al (2000)	1995-1999	Longitudinal survey	18 local authorities	2,540	1,168	Data collection at admission by the social worker, directly from care homes and the Office of National Statistics.
Sidell et al (1997)	1996-1997	Multi-methods	Three areas (Northwest, Southeast and West Midlands)	Current resident population 8,314	1,940 current residents	Postal survey (1,000 homes), interviews (100 care home heads) and case studies (12 purposively selected homes).
Rothera et al (2002)	1997-1999	Retrospective cohort	Nottingham Health Authorities	2,180 residents who died in the 12 months prior to the survey	884 deaths	Data on all admissions aged 65 or older to nursing, residential and dual registered homes, funded by social services were collected
McCann et al (2009)	2001	Prospective Census –based cohort study	Northern Ireland	1,888 residents	499	Five year follow up of people (aged 65 and over) identified in the 2001 census as living in care homes. They had not been living in a care home the year before the census.
Bowman et al (2004)	2003	Census	244 BUPA care homes	15,483	11,335	Census form completion on admission by a senior member of staff.
Froggatt and Payne (2006)	2003	Action research study	One English county		Not given	Postal survey of 261 care home managers with a telephone follow up call. Data regarding the details of residents dying in the care home was from 73 homes.

Reference	Data collection date	Study design	Study location	Sample		Study method
				Total study sample	Nursing care home sample	
Clifford et al (2007)	2005	Evaluation action research approach	79 care homes (all but two had nursing beds) participating in the GSFCH programme	365	188	75 after death analysis forms pre the GSFCH programme.
Hockley et al (2008)	2007-2008	Realistic evaluation	Seven nursing care homes using the GSFCH programme in Midlothian	228	228	Retrospective review of notes concerning the last eight weeks of life of all permanent residents by the author.
Shah et al (2010)	2008-2009	Cross sectional analysis	326 English and Welsh General Practices	435,568	4,563	A cross sectional analysis of an established primary care database-compared care home residents, aged 65 and over, with a community control group.
Forder and Fernandez (2011)	2008-2010	Retrospective review of records	All residents who died in 305 Bupa homes in the UK	11,565	82.9% of beds were nursing care home	Retrospectively reviewed records of all residents who died.
Lievesley et al (2011)	2009	Census	All Bupa homes in the UK, Australia and New Zealand – only UK accounted for	15,875	11,575	2009 census across all Bupa homes.
Shah et al (2013)	2009-2010	Cohort study	England and Wales GP practices	354,306	4,109	Description of mortality and predictors in nursing care homes, in comparison with older people living in the community using an established primary care database.
Kinley et al (2013b)	2008-2011	Cluster Randomised Controlled Trial	38 nursing care homes in south-east England	2,444	2,444	Retrospectively reviewed records of all residents who died.
Stewart et al (2014)	2010-2012	Survey	15 care homes of which four were nursing care homes south –east London	301	126	Survey of dementia, depression and behavioural problem prevalence and severity using specified assessment tools.

Table 2.3: Nursing care home residents: demographics and diagnosis (UK studies)

Study	Sex/Age	Diagnosis					
		Dementia	Stroke	Cancer	Circulatory/ heart problems	Frailty	Other
Sidell et al (1997)				9%			
Dale et al (2001)	Mean age on admission and death was 75 and 80 yrs in males and 81 and 84 in females respectively.						
Mathews and Denning (2002)		72%					
Bowman et al (2004)		38% (only 19% had a normal mental state)	22%	5%		22%	
Clifford et al (2007)		15.9%	22.8%	24%	11.9%		
Hockley et al (2008)	1/3 residents were in their 90s. Age range: 66-103yrs.	66% (main diagnosis)					
Shah et al (2010)	Mean age (SD) 84.8 (7.7) from n=4,558 26.4% male (n=1,204)	40.8%	21.3%	9.6%	Coronary Heart Disease 18.6% Heart failure 8.3%		Depression 23.5%; Diabetes 13.5%; Hypothyroidism 12.3%; Asthma or COPD 9.5%
Forder and Fernandez (2011)	67% female Over 85 (51.9%): aged 75-84 (38.6%); aged 65-74 (9.5%)						
Lievesley et al (2011)	95 and over (9%): aged 85-94 (39%); aged 75-84 (33%); aged 65-74 (12%); under 65 (7%)	45%	23.1%		Heart disease 22.3%		All neurological 78.3%; Arthritis 18%; Diabetes and endocrine 15.4%; Fractures 12.9%; Depression 10.6%; Osteoporosis 9.6%; Parkinson's 5.4%
Kinley et al (2013b)	61% were female Mean age 85yrs Age range: 33-107yrs	47.5% A further 31.1% had cognitive impairment	32.7%	23.7%	Heart disease 43.8%	3.8%	Other 53.8%; Muscular skeletal 34.5%; Functional mental disorder 22.8%; Diabetes 20%; Urinary and gynaecological 18.7%; Respiratory disease 16%; Lower GI problem 10.5%; Neurological disorders 9.7%; Upper GI problem 5.3%; Skin 4.1% Depression 29.6%
Stewart et al (2014)	73% were female Under 80yrs 43.7%; 80-90yrs 36.5%; over 90yrs 19.8%	77%					

These published papers (Table 2.3) highlight that in UK nursing care homes very few residents were less than 65 years (Lievesley et al 2011). Most residents were aged 84 years and over (Shah et al 2010, Forder and Fernandez 2011 and Kinley et al 2013b) and female; overall proportion 69% (Shah et al 2010, Forder and Fernandez 2011, Kinley et al 2013b and Stewart et al 2014). Not surprisingly residents' age seemed to be increasing. In 2001, Dale et al reported the mean age at death was 80 in males and 84 in females. A study undertaken several years later, by Kinley et al (2013b) reported that the mean age of residents who died was 85 years (range 33-107). The age of residents reported in Kinley et al (2013b) study was as great as 107 years of age. This supports the notion that the numbers of frail older people in care homes, as defined by the Department of Health in 2001 (Department of Health 2001), are increasing.

Bebbington et al (2000) reported that whilst some residents were independent and alert during each stage of their survey (6, 18, 30 and 42 months after admission) only 1% of residents were in this condition at every stage of their survey. The findings from Hockley et al (2008) and Mathews and Dening (2002) all suggest that the majority of nursing care home residents have some degree of cognitive impairment with a significant proportion having a diagnosis of dementia. The Medical Research Council's Cognitive Function and Ageing Study is collecting data from people over 65 years in a large longitudinal multicentre study looking at the health and cognitive function of older people. It is from this study that Mathews and Dening (2002) report that the prevalence of dementia in institutional care is 72% (Table 2.3). This is notably higher than the 38% occurrence reported by Bowman et al (2004) in the Bupa nursing

care home residents included within their study. A more recent study in nursing care homes supports dementia prevalence at 77% (Stewart et al 2014).

Interestingly, and perhaps importantly dementia prevalence in nursing care homes does not increase with age (Mathews and Denning 2002). This suggests that whilst the population living in nursing care homes is, and will become older, care provision will need to take account of the increasing levels of physical frailty alongside the already high level of mental frailty, of their residents.

Over time the percentage of residents diagnosed with specific medical conditions has increased (Table 2.3). For example whilst Bowman et al (2004) reported that 22% of residents had a stroke, by 2013 this had risen to 32.7% (Kinley et al 2013b). Similarly heart disease increased from 11.9% (Clifford et al 2007) to 43.8% (Kinley et al 2013b). Three studies provided specific details of many of their residents' diagnosis (Shah et al 2010, Lievesley et al 2011 and Kinley et al 2013b). Where percentages are reported across these studies the pattern of an increase in medical conditions is repeated across other diagnoses including: diabetes, depression and muscular skeletal. Hockley et al (2008) reported that 51% of residents had multi-morbidities with three or more diagnoses whilst Kinley et al (2013b) reported a median of four medical diagnoses. Kinley et al (2013b) report that poor recording of all diagnoses in nursing care home records means disease prevalence is likely to be higher. This multi-morbidity, alongside increasing numbers of residents requiring 24 hour personal and nursing care suggests that residents' physical frailty may already be increasing.

Sidell et al (1997) were the first to look at the characteristics of residents in the dying period. Over a six month period the managers of 53 nursing care homes identified the causes of death for their residents as general deterioration (51%), an acute episode (34%) or a sudden death (6%), with 9% of all people who died having a terminal diagnosis. Seven years later, Bowman et al (2004) reinforced the finding that the percentage of residents dying with a terminal diagnosis (cancer diagnosis) is low (Table 2.3). This trend seems to be one that continues with Hockley et al (2008) reporting the least common cause of death was a terminal diagnosis with the majority having a dwindling trajectory. Twelve years after Sidell et al (1997) study, Kinley et al (2013b) used their classification for type of death and reports a similar proportion of residents dying from a dwindling death (50.3%) and sudden deaths (4.3%) but a change across acute deaths from an earlier 34% to 19.2% and from terminal deaths, 9% to 26.2%.

The incidence of residents dying with a cancer diagnosis (24%) that Clifford et al (2007) reports is considerably higher than that reported by Sidell et al (1997), Bowman et al (2004) and Hockley et al (2008) (Table 2.3). However, the data from Clifford et al (2007) was generated from the five most recent deaths, in a six month period. It may simply reflect the fact that residents with cancer had a shorter prognosis than their residents with other medical conditions. Alternatively, it may be a reflection of the recent development of continuing care beds being provided within some nursing care homes, impacting on their resident population. The relatively short admission period, with one in five residents dying in the nursing care home within the month, may also suggest this. A similar incidence is reported by Kinley et al (2013b) who

collected data in 38 nursing care homes from 2008-2011. They report that 23.7% of the 2,305 residents who died during this time period had cancer.

Table 2.4: Nursing care home residents' mortality

Reference	Death/ mortality rate	Median survival	Other mortality figures	Factors associated with survival	
				Increase survival	Decrease survival
Sidell et al (1997)	Death rate per year is 36%.		54% die within two years of admission.		
Bebbington et al (2000)		1 year			Admission - 30% of deaths occurred within three months of admission.
Dale et al (2001)		5.9 years	17.5% died within 12 months of admission. Mortality in nursing care homes is accounted for by resident demographics not care site. Only 41 of the 59 nursing care homes had a death in study period.	Survival to the second year meant their chances of dying in this year halved when compared with the first year.	Significant predictors of mortality were increasing age, male gender, poor appetite, sleep disturbance, build, place of admission from, history of malignancy, respiratory disease and number of prescribed drugs. Malignancy, pressure sores, poor appetite and number of prescribed drugs predicted death within four weeks of admission.
Raines and Wight (2002)			Mortality of admissions from hospital and the community were only statistically different in 1993.	Survival time over years increased.	16.5% of total sample died in the first month of admission. Concluded mortality is not related to source of admission.
Rothera et al (2002)	1 year mortality rate 41%.	1.48 years		Mortality rates decreased with length of stay.	Decreased life expectancy associated with male gender, placement from hospital, decreased mobility and increased age. Lack of cognitive impairment was associated with lower survival.
Froggatt and Payne (2006)			53% (n=252) of residents who died in the nursing care homes had lived there for more than a year.		
Clifford et al (2007)			60% of residents lived in the nursing care home for one year or less before they died.		One in five residents had been in the nursing care home for four weeks or less before they died.
Hockley et al (2008)			The majority of residents died within two years of admission.		
McCann et al (2009)		2.33 years (95% CI 2.25- 2.59)	Death rates may not be an appropriate quality measure for this population.		Mortality in nursing care homes was 2.9 times higher than equivalently aged people in the community.
Shah et al (2010)			Less than one year registration n=1,051 (23.1%).		

Reference	Death/ mortality rate	Median survival	Other mortality figures	Factors associated with survival	
				Increase survival	Increase survival
Forster and Fernandez (2011)			Mean (adjusted) length of stay from admission to death was 762 days (no range given)	The chance of living for a year after admission was associated with gender and bed-type – higher for females and frail elderly.	The chance of living for a year after admission was associated with gender and bed-type – lower for men and for residents with dementia.
Shah et al (2013)	1 year mortality was 30.8%		Mean registration length 9.2 years	Adjusted for age and sex, nursing care home residents experience four times the expected mortality of community residents.	
Kimley et al (2013b)	1 year mortality was 56%	8 months (range 1-6,393 days)	19% died within their first month of admission 34% died within the first three months of admission		

Of the 17 identified studies, 13 make reference to a resident's length of stay in the nursing care home (Table 2.4). Five of these report the number of residents who die one to three months after admission (Bebbington et al 2000, Dale et al 2001, Raines and Wight 2002, Clifford et al 2007 and Kinley et al 2013b). The Department of Health funded a longitudinal study that followed 2,540 people admitted into long-term residential and nursing care homes, within 18 local authorities, from October 1995-January 1996 for 42 months (Bebbington et al 2000). Of the 46% admitted to nursing care homes, the median survival was 12 months. They found that death rates were particularly high during the first few months of admission, - 30% of residents died (Bebbington et al 2000). This proportion varies: Raines and Wight (2002) reported the percentage of residents dying within one month of admission as 16.5% whilst in 2007, Clifford et al (2007) reported this as 20% and Kinley et al (2013b) similarly as 19%. What is evident from Table 2.4 is that the median survival time of those residents who died is decreasing. In the most recent study Kinley et al (2013b) reports median survival as 8 months which is considerably less than across the other studies reporting on this. Nursing care homes are clearly no longer only a place to live.

These 17 UK studies detail that the population residing in nursing care homes have: increasing age: increasing physical and mental disability, multi-morbidities and a poor prognosis. This complexity of need presents a challenge to the provision of care in the institutions in which they reside.

2.4.4: Nursing and residential care homes as a place to die

The proportion of the population dying in care homes in England is increasing, reflecting the increasing numbers of deaths of older people and residence of older

people in care homes. In 2005, 16.2% English population were dying in care homes with 9.5% deaths occurring in nursing care homes (Tebbit 2008). By 2011, the Department of Health (2012) reported that 19.4% of all deaths in England occurred in care homes. Whilst this percentage varies considerably across the country, and alters year by year, the number of deaths within all care homes, has increased (Table 2.5).

Table 2.5: Number of deaths in England of people using adult care services by home type and financial year (Care Quality Commission 2010a and 2012)

	2003/ 2004	2004/ 2005	2005/ 2006	2006/ 2007	2007/ 2008	2008/ 2009	2009/ 2010	2010/ 2011	2011/ 2012
Residential care home	25,568	26,184	24,726	26,949	25,709	28,623	29,108	16,233	30,410
Care home with nursing	49,762	48,275	46,735	49,161	47,218	52,568	85,029	49,477	93,748

The data presented in Tables 2.1 and 2.5 highlight that significant numbers of older people are entering residential and nursing care homes and then dying whilst resident there. In England, from April 2008-March 2009 there were 260,488 residents in residential care homes and 192,681 residents in nursing care homes (Table 2.1). Although the data in both Table 2.1 and 2.5 fail to account for vacant beds, it could be approximated that by 2008/9 11% (n= 28,623) of residents in residential care homes died and 27% (n=52,568) of the residents in the nursing care homes. In 2011/2012 this increased to 12% (n= 30,410) of the residents in residential care homes and 43% (n=93,748) of residents in nursing care homes. The increasing numbers of deaths in care homes, in particular nursing care homes, highlight a need for greater provision of care at the end of a person's life.

In England, a large proportion of the lifetime cost to provide health care for an individual is reported to occur in their last 18 months of life (Barker 2014). Its provision is clearly costly, but the current division of health and social care also makes it complex, as at the end-of-life, distinctions between health and social care are hard to identify. If the new model of care provision that the Burstow (2014) report recommends does emerge, then so may the model of end-of-life care delivery for those residents needing end-of-life care.

2.5: End-of-Life Care

The provision of palliative care within a country is affected by its culture, traditions, existing healthcare frameworks and resources (Singer and Bowman 2002). This means that despite the World Health Organisation providing an international definition (World Health Organisation 2013), worldwide palliative care has variable recognition and consequently national, not international, interpretation and provision.

Within the UK, there are a variety of phrases pertaining to care given at the end-of-life including: palliative care, specialist palliative care (SPC), terminal care and end-of-life care. Despite the use of these terms within the UK literature, the terminology is acknowledged to lack clarity and be poorly understood (Commissioning Guidance for Specialist Palliative Care 2012). The use of these terms interchangeably throughout the international literature has resulted in further confusion with both definitions as well as service provision. The decision to use the term end-of-life care in this thesis is now discussed.

2.5.1: End-of-life care (England)

The term end-of-life care is defined and used within the Department of Health (2008) strategy promoting high quality care for all adults at the end-of-life. This document quotes the National Council for Palliative Care:

‘End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’ (Department of Health (2008:47).

Within this strategy it also acknowledges that the start of end-of-life care varies and may be identified by the patient, or by the professional caring for the patient. It may occur at: the diagnosis of a condition, where the person has a poor prognosis; where a chronic condition has progressed and the prognosis is likely to be a maximum of a year or two; when elderly people become frail and need care at home or enter a care home (Department of Health 2008). The term end-of-life care incorporates palliative care, has arisen recently and so is not historically associated with cancer care; it covers all settings and all chronic conditions with a poor prognosis. These factors, especially the recognition and inclusion of frail older people in care homes, are why the phrase end-of-life care, and not palliative care, has been chosen for this thesis.

2.5.2: Care homes in relation to end-of-life care

Care home staff now have a very complex role caring for increasingly frail residents (Owen et al 2012). Redfern et al (2002) identified that staff in one nursing care home

in London found coping with death and residents' pain and distress caused the most stress. However, in contrast, subsequent research has shown that when staff are given the appropriate support and responsibility, care assistants feel more valued when caring for residents at the end-of-life (Hockley et al 2005). However, many carers are never informed prior to working in a nursing care home about the frailty of the residents they will be caring for. Hockley (2006) reported that carers just assumed that they will be helping older people to wash and dress, brush their hair and help them with their food.

Routine training within a care home setting does exist and consists of induction and mandatory training. Mandatory training is carried out on issues such as manual handling, nutrition and managing vulnerable adults. However, palliative care training or end-of-life training is not mandatory, even though the majority of older people die within two years of admission to a nursing care home (Sidell et al 1997). Sidell et al's (1997) postal survey to care home managers stated that 66% staff had some training in palliative care. However, the case study observations revealed that training was extremely limited. Komaromy et al (2000) findings are supported more recently by Watson et al (2006) and Whittaker et al (2006).

The rehabilitative culture in nursing care homes, referred to by Hockley (2006) would now seem inappropriate in light of residents increasing frailty (Tables 2.3-2.4). Nursing care homes are places of care that are now providing, and will be expected to provide, care to increasing numbers of dying older people. This increasingly frail, dependent population now requires an alternative approach that still incorporates care provision while living but also for increasing numbers when dying.

2.6: Recommended tools and frameworks for the provision of end-of-life care in care homes

Within the Department of Health (2008) strategic document the emphasis that all settings, including care homes, need to provide end-of-life care was accompanied by suggestions as to how this might be achieved. The specific end-of-life care tools and frameworks they listed for achieving change in care homes included the GSFCH programme. Whilst the GSFCH programme is the focus of this thesis, it incorporates the Liverpool Care Pathway (LCP) with education and training and so these elements are also described.

2.6.1: The Gold Standards Framework in Care Homes programme (GSFCH)

The Gold Standards Framework (GSF) programme is a system-based organisational approach to optimising the provision of end-of-life care. It was initially used in primary care and was intended to act as a guide for generalist providers in the community (Thomas 2003). Similar to the GSFCH programme, the GSF programme within primary care is also promoted in English policy (Department of Health 2008). Despite the widespread promotion of GSF in primary care since 2000, there has been limited evaluation of the programme. Whilst the level of adoption of the GSF into primary care is high, and by 2007 over 3000 GP practices had committed to the programme, there is wide variety in its implementation (Munday 2007). A critical review of the impact of the GSF by Shaw et al (2010) revealed that 10 years after its introduction into practice, evidence was available from all phases of the GSF programme in relation to the effectiveness of the programme. There was less evaluation of the appropriateness or feasibility of the programme. The GSF in primary care programme has three levels of implementation; foundation, higher and advanced (Shaw et al 2010). In Shaw et al's (2010) review, most GP practices had achieved the

foundation level of the GSF. This achievement may reflect the effect of quality payments, which encouraged adoption of these foundation level components, rather than its value as an intervention (Munday et al 2007). It was also acknowledged that the quality of evidence meant factors other than the GSF may have influenced the findings (Shaw et al 2010).

Petrova et al (2010) explored the relationship of facilitation to implementation of the GSF programme in primary care. They reported that from 2003-2005, 1305 GP practices were being supported by 171 facilitators who had received national standardised training. Facilitators were locally appointed, but supported through the GSF national team via workshops, a newsletter, website resources and an advice line. Despite this national standardised training, Petrova et al (2010) reported variety in the way facilitation was being provided. With regard to facilitation and implementation of the programme, the practices facilitated by a GP were reported to have achieved higher levels of implementation of the recommended palliative care processes in place than those facilitated by a Clinical Nurse Specialist.

GPs involved in the original GSF primary care pilot suggested an extension of the programme into care homes. GPs thought it could help them to work together with the care home staff to provide better end-of-life care to their residents. In 2004, the Primary Care GSF programme was adapted to provide a framework for care homes (GSFCH) referred to as the *Phase 1* GSFCH programme. Thereafter the GSFCH programme has been run yearly with a new phase of the programme starting each year. Although developed in the UK, international interest has resulted in the

development of policy to enable worldwide implementation of the GSFCH programme (GSF Central Team).

The GSFCH focuses on highlighting the importance of dimensions, usually known as the 7Cs, in end-of-life care. The 7Cs are: Communication: Co-ordination: Control of symptoms: Continuity: Continued learning: Carer support: and Care of the dying. The three aims of the GSFCH programme are:

1. To improve the quality of care for people nearing the end of their lives
2. To improve collaboration between care homes, primary care and palliative care specialists
3. To reduce inappropriate hospitalisations of residents at the end-of-life

Given these aims, the GSFCH programme clearly has relevance to the current nursing care home population. However, to achieve these aims, it would be important to take into account the demographics of the nursing care home residents identified earlier. This has started to occur, and changes to the GSFCH programme have been made. For example, dementia is a key standard within the GSFCH programme. Previously care of residents with dementia was taught in one session in one of the four workshops. As the majority of residents within nursing care homes have dementia or cognitive impairment, the structure of the current Good Practice Guide (National GSF Centre 2014) has altered with a focus on learning objectives, rather than workshops. This now means the care of residents with dementia is prominent across all four workshops. Despite this change, the GSFCH Good Practice Guide still has omissions in relation to best practice. It should contain up to date knowledge and recommendations. A recent initiative, for example, includes the Namaste care

programme for residents with advanced dementia (Simard 2013; Stacpoole et al 2014). At a minimum, reference to this should be included in the core GSFCH programme literature. This is not the case.

The GSFCH programme consists of three distinct phases: the Preliminary Phase, the Implementation Phase and the Consolidation Phase (Gold Standards Framework Centre CIC 2011).

The Preliminary Phase provides a preparation time, so that awareness of the GSFCH programme can be established both within the care home and between the care home and their external professionals. During this phase care home managers are asked to hold internal meetings for staff, family and residents to inform them about the GSFCH programme. Managers are encouraged to send letters about the GSFCH programme to residents and families as well as to external Health Care Professionals including their GP and SPC service. Templates for letters are provided by the GSF central team, to help them with this process, as well as a DVD to show the staff. This phase usually occurs over a three to six month period.

The Implementation Phase, the second phase, is run over nine months. It consists of four workshops which nominated care home staff (known as the GSFCH coordinators) attend and who take responsibility for implementing the programme. The GSF central team suggest a further meeting is held and organised locally for all nursing care home GSFCH coordinators between each workshop. From the information provided at the workshops the care home managers and staff are encouraged to adopt the principles of the GSFCH at a pace that suits the home. The

aim is to gradually incorporate the framework during this nine-month period, until it becomes standard practice. Whilst the initial training is in the workshops, the training needs to be translated into learning in practice, by the entire care home staff. Central to this phase is establishing monthly review meetings where all residents are discussed. Each resident is coded according to the time that staff feel they have to live ('A' = years, 'B' = Months, 'C' = weeks and 'D' = days). The code then shapes the care individual residents require.

The Consolidation Phase is the final phase of the GSFCH programme. It consists of consolidation and sustainability, where the principles of the GSFCH become embedded in the care home culture, as the care home staff work towards accreditation. To achieve accreditation, the manager and staff compile a file of evidence pertaining to 20 specified standards. The GSF central team suggest this phase takes between nine to twelve months to complete (Gold Standards Framework Centre CIC 2011). Re-accreditation then occurs on a three-yearly basis.

2.6.2: The Liverpool Care Pathway (LCP)

The End of Life Care Strategy (2008) recommends the implementation of the LCP documentation to help guide care delivery in the last days of life. The LCP was developed in the UK in 2001, as a tool to enable the principles of end-of-life care in the palliative care setting, to be delivered by other professionals in other care settings (Ellershaw 2002). It is an example of an Integrated Care Pathway (ICP). Integrated Care Pathways are multidisciplinary documents that detail essential steps in caring, for specific groups of patients, with a specific clinical problem (Campbell et al 1998). Such a document enables practitioners to provide individual, consistent and

measurable standards of care. Deviation from the standard care is permitted by recording a 'variance' and documenting the reason for this. An ICP incorporates expert opinion, evidence-based practice, research, guidelines and protocols and outcomes are tied to specific interventions. The LCP design reflected this. It is a multi-professional document that provides an evidence based end-of-life care tool to guide, prompt and inform the care of patients and their families in the last days of life (Jack et al 2003). It has been adopted internationally with 18 countries outside the UK utilizing it (The Marie Curie Palliative Care Institute Liverpool 2012) and several European countries; across a range of care settings evaluating it (Constantini and Lunder 2012).

Following a national review of the LCP in England, (Neuberger 2013) the use of the LCP in clinical practice is to be disbanded. In 2012, a number of relatives of patients with whom the LCP had been used, raised concerns about its use which led to its value being questioned and debated. A supportive statement was finally released following this debate that clarified its role and supported its worth, as a framework for the delivery of high quality end-of-life care (Royal College of Nursing 2012). However, information on guidance for its implementation and evidence of its outcomes remained sparse. A decision has been made to remove the LCP from clinical practice in England in all settings (Neuberger 2013). The controversy that has led to this decision highlights the importance of ensuring that any tool that replaces the LCP is properly implemented into practice using innovative training methods alongside measurable outcomes. This should be the case when implementing any new initiative into clinical practice.

2.6.3: Education and training

Although it is the manager on behalf of the care home that commits to the GSFCH programme, not an individual, the implementation of the programme does initially occur through the educative workshops education, delivered to the nominated GSFCH coordinators of the care home. Training differs from education. It relates to where there is some specifiable type of performance that has to be mastered, practice is required for the mastery of it and little emphasis is placed on the underlying rationale (Peters in Tight 2002). This was what the GSFCH programme intends for all members of staff in the care home. Both education and training should be provided within the home by the GSFCH coordinators supported by an external facilitator.

The education and training approach taken by the GSFCH programme is supported by Katz and Peace (2003). They identify that education and training are both important and that in order to deliver care to dying residents effectively care home staff need:

- Knowledge - to understand how older people experience dying
- Skills - with communication, defining dying, basic pain control and symptom relief and bereavement care
- Behaviour - in that they know how to access palliative care services for equipment, advice, support and training

If education and training are both important, as Katz and Peace (2003) suggest, then implementation of an intervention into practice such as the GSFCH programme, needs to take account of both. Imparting knowledge alone without paying attention to skills and behaviour will not change practice. Such a concept is supported within a more

recent review of the literature which stresses the importance of addressing staff attitudes and perceptions when providing education and training (Nolan et al 2008).

The Burstow (2014) report has recognised the need for better delivery of good care by all, with the recommendation that all staff have a minimum level of training and development. They recommend an accreditation care certificate that would be linked to a licence to practice. This would ensure a basic level of knowledge and skill by all members of staff in organisations providing ‘housing with care’ before they attend end-of-life care training.

The care certificate also introduces the concept of individual accredited courses, and it may be this means an accredited end-of-life programme is correspondingly important. Alternatively, it may be that individuals opt for individual training where they gain an accreditation certificate, rather than investing their time and energies in bringing about change for the accreditation of an entire care home. If this is the case, implementing a systems based, cultural change, end-of-life care education and training programme may be more challenging. The GSFCH Programme may need to reconsider and provide accredited recognition for the specific individuals in a care home, for example, the GSFCH coordinators, leading the implementation of the GSFCH programme.

2.7: Conclusion

The current and predicted global population has implications for care and service provision. Care homes have been highlighted as places of care for the increasing number of older people, particularly the oldest-old, of our society. Care home staff

will need to continue to meet the health care needs of their residents. With the changes in patient demographics and policy this will need to incorporate the provision of end-of-life care. In order to do this it will require change. The next chapter details how this might be achieved; the specific role that facilitation has in achieving such organisational change is also considered.

Chapter Three - Organisational change

Change needs to occur in care home settings in order for care provision to continue to meet the needs of frail older people in the UK. Initially in this chapter the concept of organisations and organisational change is discussed. Culture in care homes, in relation to change, is also considered. Whilst organisations are always in a state of continuous change (Evered 1980) the importance of understanding an organisation, prior to the initiation of a specific change intervention, is highlighted. Soft Systems Methodology (Checkland 1999) is used here to illuminate how care homes as organisations function (both internally and externally with their wider community) before such a change initiative is introduced. Obtaining this detailed understanding enables the important three core dimensions that Kitson et al (1998) identified to be considered when implementing new knowledge into practice: the care context; the role of facilitation; and, the quality of evidence about the change initiative to be more appropriately understood for the specific organisation undergoing change. In this chapter the care home context is considered in relation to change and an evaluation of the role of a facilitator when implementing change in an organisation is explored. In Chapter four the quality of evidence being implemented is discussed following an examination of the literature.

3.1: Organisations and culture

Organisations are social systems established in order to achieve a particular goal or task. They are consciously established, at a defined moment in time for an explicit purpose (Silverman 1970). All organisations develop an internal system of working. Organisations are recognised as having rules and structures, or formal ways of doing

things as well as informal ways of behaving and acting, their culture (Sedan 2003). Gubrium's ethnographic study demonstrated the importance of recognising both the importance of the culture of an organisation as well as the organisation's rules and structure 'To understand how reasonable much of everyday life is, even what seems at first glance, to be 'crazy,' the context or place in which it occurs must be taken into account' (Gubrium 1975:158).

Organisations may have subcultures. These are organisational layers that develop in complex organisations in relation to culture, occupation and divisional units (Scott et al 2003). Subcultures, may not always be recognised, but they should be considered; where present, they may not be fully orientated to the organisation's culture or even in conflict with them. However, in addition to internal systems of working, organisations are also tied to and have links with society. Thus an additional layer of complexity to understanding organisations is added. Organisations not only have their own internal environment with subcultures, but are also made up of the various links they have with their external environment.

'An organisation is experienced as a living, dynamic and interactive place. This is shaped in turn by its relationship to external factors such as other organisations, the clientele, law, social policy and public opinion'(Sedan 2003:108).

Sedan (2003) identifies organisations as unique and complex. Not surprisingly, understanding how they function is also complex.

3.1.1: Learning organisations and cultural change

Organisational theory developed during the British Industrial Revolution in the late 18th century (Burnes 2009), in response to factory owners aiming to maximise profits. To do so they introduced a linear, task-focused system of work, under a hierarchical management structure. This was known as the classical approach to organisations where management occurred by force and imposition which was often met by resistance from staff (Burnes 2009). Employees were only seen to be valuable in terms of their output.

The human contribution to organisations and organisational change was initially recognised in Mayo's work in the 1930s with his Hawthorne Experiments (Burnes 2009). This in turn led to alternative approaches to organisational management. Central to these models is recognition of the human element within organisations and the pivotal role played by human beings. As a result employee's worth was seen in relation to their knowledge, as well as their work performance. Rather than controlling the employees the organisation instead continually learnt from, and with, them. Individual learning still occurred but this learning was harnessed by and embedded into the organisation, so that it contributed to organisational change (Holmqvist 2003). From here, the concept of a learning company emerged (Pedler 1989:2). Recently the term 'learning company' has been reframed by Senge et al (1994) to the term 'learning organisations'.

The learning organisational model, has an ongoing, unending, impetus for change. It is not training or enforced change, but collective internal learning at the organisational level, that results in transformation. Achieving this is only possible with cultural

change, where change has not only occurred, it has become totally embedded into practice. When this is the case, it is much more likely that any change is maintained and sustained.

One of the disciplines underpinning a learning organisation model is systems thinking (Senge et al 1994). Systems thinking helps ensure that both the internal and external relationships of an organisation are both considered, when bringing about change; information sharing and joint learning with others in the external system not just the internal system needs to occur (Pedler 1989). However, in addition to systems thinking four other disciplines are also recognised: personal mastery, mental models, shared vision and team learning (Senge et al 1994). These additional disciplines are concerned with creating and driving forward a future vision that everyone sees, commits to and recognises that they must work together in order to achieve. It would seem for organisations to become learning organisations, as defined by Senge et al (1994), leadership is crucial.

From the description given above organisations are recognised to be both complex and unique. To understand how they function requires not only knowledge of their rules and regulations but also an understanding of their culture, as well as their external environment.

3.2: Organisations as systems

The complexity of organisations means that achieving change within any organisation is difficult. Attempts to introduce change into organisations often fail. Burnes (2009) reported that 90% of culture change initiatives, 40-70% of technology change

projects, and, 90% of total quality management initiatives fail. Over time, organisations have been understood using different conceptual lenses that include: scientific management; human relations; bureaucratic; power, conflict and decisions; technology; systems and institutional (Bate 1994). In this study systems theory is used to better understand organisations because it takes account not only of an organisation's internal and external systems but also the relationships between them (Senge et al 1999 and Wilson 1992).

3.2.1: Systems theory

The origin of systems theory is attributed to a biologist Ludwig von Bertalanffy (Bertalanffy 1968). Systems theory occurred with the realisation that it was the sum of and the interplay of components, that resulted in a completed product, not the production of singular components. Bertalanffy (1968) is credited with defining the difference between a closed and an open system. In closed systems, the final state is unequivocally determined by the system's initial internal conditions. In open systems, however, there is recognition that systems containing individuals will interact with their environment. This means the final condition of the system is likely to be reached in varying ways. In open systems change that occurs within the organisation, is also affected by the relationships that exist between them and their surrounding environment (external systems).

As well as systems being defined as closed or open they can also be described as hard or soft. These terms relate to how an activity is undertaken (Wilson 2001) or the method taken to solve a problem (Lewis 1994). Within hard systems an operational research, systems analysis or systems engineering approach is taken by an analyst to

investigate complex situations and determine the best course of action from a number of alternatives (Lewis 1994). The role of the analyst is one of problem solving for the client – identifying potential solutions to a problem and listing the activities that would best solve it. It involves manipulation of the quantitative aspects of a situation to best stimulate a real world situation. They do not take account of the influence of the solution in practice; and, evaluation of the intervention is usually determined by those funding the analysis not by consensus opinion of all those involved (Lewis 1994). Wilson (2001) acknowledges that an organisation becomes a much more complex situation when the people within the organisation are also taken into consideration. When human beings are incorporated into a problematic situation that needs resolving Soft Systems Methodology offers an alternative approach.

3.2.2: Soft Systems Methodology

Unlike in hard systems, Soft Systems Methodology does not seek to solve ‘the problem’ but to facilitate a learning process which allows everyone involved in the problem to gradually develop a more comprehensive understanding of the situation under study before action is taken. It enables mapping an understanding of what a complex organisational unit is doing and therefore is valuable prior to initiating change, as it enables an organisation’s current situation to be understood before implementing a change initiative. Soft Systems Methodology takes account of the organisation undergoing the change (**C**ustomer), the person implementing the change (**A**ctor), the process of change (**T**ransformation), any external worldwide influences (**W**orldview), management factors (**O**wner) and any environmental factors

(Environmental constraints) – collectively referred to as CATWOE¹ (Checkland 1999).

The aim of Soft Systems Methodology is to bring about improvements in a situation perceived as problematical. The centre of concern is a situation that someone has noted to be problematic and believes it to be worthy of taking action to improve it (Checkland and Winter 2006). Checkland and Winter (2006) provide an example of how Soft Systems Methodology was used in the NHS to re-think the provision of children's services in Manchester. Soft Systems Methodology lends itself particularly well to dealing with complex situations, where those involved lack a common agreement on what constitutes the problem needing to be addressed. As a result, many different perspectives, values, and beliefs exist around what aspects of the situation are most important and how to address them. Additionally, in such situations, the various aspects perceived as problematic tend to be highly interrelated; therefore changing one aspect is likely to have knock-on effects on other aspects. In such situations it is important to develop a reasonably comprehensive understanding of the inter-relationships of the various aspects of the problem situation alongside its context. Unlike in hard systems, where different interpretations of the problem become conflicting objectives, in soft systems these opinions are actively sought (Lewis 1994).

Soft Systems Methodology provided a conceptual framework that would enable the research questions for this study to be answered. The study took place in complex

¹ CATWOE refers to the organisation undergoing the change (Customer), the person implementing the change (Actor), the process of change (Transformation), any external worldwide influences (Worldview), management factors (Owner) and any environmental factors (Environmental constraints).

social organisations, nursing care homes, and aimed to understand the implementation of a complex change intervention. In addition, implementation of all the components of the GSFCH programme could vary, and the nursing care home may or may not have the support of an external facilitator. What helped, who helped, and how they helped in the implementation of the two year programme was not known. The process of implementation of such a programme could only be understood by taking a broad approach. Capturing details about one part of the system may have meant an important aspect was missed. The systems wide approach helped minimise this. Its aim was to give an understanding, which in conjunction with the CRCT findings may offer an answer to the process of cultural change and the outcomes that result. As change was needed to implement the GSFCH programme it was important to consider how the process of change usually occurs in a care home setting.

3.3: Care homes in relation to organisational change

Change does not happen on its own; there is always a source that has initiated the change. In order to understand how such change is initiated in care homes, the three forms of change that Iles (2006) identifies are considered namely: planned or deliberate change; emergent change; and, spontaneous change.

3.3.1: Planned or deliberate change, emergent change and spontaneous change

Planned or deliberate change refers to organisations recognising an area that they believe needs changing and instigating a process to achieve this (Burnes 2009). This process includes devising a plan of action that is implemented, monitored and has outcomes that are evaluated (Iles 2006). There are some examples of planned or deliberate change occurring within care homes. One such example occurred in the

USA in the 1990s, where a review of resident death certificates identified 22,000 care home residents' deaths as attributable to malnutrition (Robinson and Gallagher 2008). Problems were traced back to reporting and recording of events in the care home. This led to the implementation and enforcement of guidelines and quality indicators.

In the UK, care homes are monitored by their regulatory body, the Care Quality Commission (CQC) against 28 regulations and outcomes (Care Quality Commission 2010b). The CQC undertakes regular audits of the provision of care provided within a care home. If staff in the care home fail to meet a particular standard, change strategies will be put in place. These are then enforced by repeated monitoring, fines, public warnings or closures (Laing 2012).

In the two examples, given above, the need for change has not emerged from within the care home itself, but in response to the care home's external systems. This form of change induces compliance, but not necessarily learning. Planned or deliberate change is like the 'single loop learning' Argyris and Schön (1978) identified. Here, organisational change is in response to the detection and correction of errors resulting in a change in regulations or rules within the care homes current practice (Hayes 2010).

Emergent change on the other hand arises from the intuitive knowledge held within the organisation. It is continuous, unpredictable and cumulative. However, for change to occur there needs to be a collective vision and learning (Senge et al 1994). There are examples of willingness amongst nursing care homes to engage with this form of change, when it is instigated and supported by sources in their external system. An

example is when Hockley et al (2005) implemented an Integrated Care Pathway (ICP) alongside an action learning approach. However, what is unknown is if the emergent change (the ICP) was then sustained in practice. Emergent change has the potential to result in ‘double loop learning’ which involves modification of the organisation’s underlying norms, objectives and policies (Argyris and Schön 1978).

Finally, spontaneous change occurs in complex adaptive systems (Iles 2006). It is not planned, or part of one organisation, but the outcome of group interactions with one another. The outcome is therefore never predictable, but arises as a consequence of the relationship between the organisation and members of their external system. A recent publication by Owen et al (2012) reported that following a locally based meeting between care home staff and hospital staff, a sub-group consisting of care home managers and hospital practitioners (no further detail provided) continued to meet, with changes occurring in relation to coordination of care between these two settings. Once again the impetus for change came from the care home external system.

In the literature reviewed, the initiation of change tended to come from external factors rather than their internal system. This experience is not unique to care homes and Alvesson and Sveningsson (2008) report it to be a common feature of many organisations. The external professionals, initiating change in the care home, might have considered the level of evidence of the change they are asking the care home to implement, but they may equally have not. It would be important to take this into consideration when initiating and sustaining change in a care home setting.

3.4: Context in relation to change

When implementing research into practice, the context, is defined as the setting or the environment into which the proposed change is to be implemented (Kitson et al 1998). Kitson et al (1998) suggests three aspects should be considered in relation to context, namely: the culture of the organisation; leadership within the organisation; and, measurement (i.e. how systems and services are routinely monitored in the organisation). These are now discussed in turn.

3.4.1: Culture and change in care homes

Culture represents an organisation's deep-set values and beliefs about how work is organised and individuals managed (Handy 1999). Kotter (2007:8) makes reference to this as 'the way we do things round here'. The organisation is able to transfer these values and beliefs to newcomers joining the organisation (Anthony 1994). The culture, and the day to day work of staff within a care home varies. It may be based on practice and/or learning. This means when considering the implementation of change within a care home to understand their culture, both their practice and their learning based culture need to be taken account of.

The association between practice and learning based culture and change is illustrated by Wilson et al (2009). They identified that three types of relationships existed between residents, staff and family members: pragmatic relationships; personal and responsive relationships; and, reciprocal relationships. Where the motivation for work and day to day practice within a care home was practice based, it resulted in pragmatic relationships. Knowledge of care delivery in this care home would be through demonstration in practice and be in relation to doing a good job. The other two

relationships were different. Here, delivery of care in practice could only occur after learning had occurred. It was based on the person rather than the task that was being undertaken. This learning shaped the care practice between the staff and residents (personal and responsive relationships) and staff, residents and family members (reciprocal relationships). Learning in the later two relationships occurred through spending time, and having a desire to know more about a resident then shape the delivery of care on the basis of what was now known. Practice was not standard. Learning shaped practice. If this was subsequently adopted by all staff it led to learning based cultural change. Practice based culture was what staff knew and delivered. Learning based culture was based on wider engagement and collaboration, and had the potential to deliver ongoing change. The importance of this relationship centred approach to transforming practice has been recognised and highlighted by others (Koloroutis 2004; Nolan et al 2004; and Nolan et al 2009).

Williams (1993) suggests that culture incorporates how new observations and meanings are tested by an organisation. When change is proposed, if the organisation fully understands the change and believes that their current values and beliefs can be improved, cultural change may occur. Whilst this always requires structural change and takes time to achieve (Anthony 1994). Where it occurs, as learning has occurred by an organisation rather than through the practice of an individual, it is change that is likely to be sustained.

When implementing change in care homes, a particular challenge is getting everyone on board. When considering change, Alvesson and Sveningsson (2008) made particular reference to the existence of subcultures in organisations. Although staff are

eager for more knowledge, there is little ethos of encouraging a learning culture as a part of practice with care homes (Watson et al 2006). Work in care homes is task driven, with each post and each post holder having specific responsibilities (Sedan 2003). They are reported to have a practice based culture. A culture that is task driven, with a low regard for individuals, low morale (RCN 2011) and little or no continuing education. Redfern et al (2002) found this lack of regard for individuality of staff led to dissatisfaction at work. Nursing care homes have poor retention of staff (Redfern et al 2002). There is a lack of opportunities for job variety and opportunities to use their abilities. The majority of staff members working within the nursing care home setting are care assistants and not trained nurses. McCormack et al (2002) identify care homes as having a low culture due to a large number of untrained staff, limited cross organisational working and low staffing levels. This work pattern and their practice based learning style means there are challenges to implementing and sustaining cultural change initiatives that are dependent upon learning.

3.4.2: Leadership and change in care homes

‘Change, by definition, requires creating a new system, which in turn always demands leadership’ (Kotter 2007:60). It involves stimulating motivation by thinking ahead and driving change towards an articulated goal. Kitson et al (1998) describes leadership as consisting of four elements; clear leadership, effective organisational structure, effective team work and clear roles. In relation to clear leadership, Moss Kanter (1995: xiv) citing Follett suggested that a leader ‘sees the whole situation, organises the experience of the group, offers a vision for the future, and trains followers to be leaders.’ Whilst in the literature management and leadership are often used interchangeably they, do in fact, differ. Within an organisation, the focus of a

manager is on minimising risk and maintaining a system that produces goods and services efficiently (Shaw 2007 and Kotter 2007). It is about the present (Burnes 2009). On the other hand, leadership is more difficult to define. It is not about a position in an organisation. It is about having a vision that becomes shared. The leader motivates others within an organisation, in order to help achieve the vision. It is about creating change and the future (Burnes 2009).

However, to achieve this, those driving such change need to both behave in accordance with the new evidence being implemented as well as be included in the change process (Alvesson and Sveningsson 2008). For change to occur, the engagement and participation of three groups is essential, namely: leaders, management and followers (internal and external staff). As an organisation changes, those involved learn from the process of change and have to adapt to the new situation that they are creating. As organisations change they learn 'as we perform a certain action our thoughts towards it changes and that changes our activity' (Graham 1995: 41).

Clear leadership is key to successful change. The RCN (2011) recently reported that 33% of managers in care homes were in post for less than one year and 18% between one and two years. These statistics are not new. McCormack et al (2002) reported unstable management structures in nursing care homes alongside weak leadership, a lack of teamwork, poor organisational structures and didactic approaches to learning. Komaromy et al (2000) reported that over half of the homes in their study were managed by a rigid hierarchical system where management rather than leadership held the predominant role.

The concept of leadership by one person has been challenged by Western (2008), who suggests that leadership is a process. If this view is taken, leadership does not consist of an individual, but rather a group, an organisation or a nation. Leadership in this model moves between roles, groups and places. It is about moving forward and creating change, rather than the role of a specific individual. However, for change to occur, it needs to be supported and driven by management (Burnes 2003).

In relation to end-of-life care, care home managers influence the standards set within the home; their qualifications and beliefs around what constituted a good death; and influence how dying and death is managed. However, in a study by McCormack et al (2002) only 34% of care home managers were familiar with the hospice philosophy, while only 15% had a detailed understanding of palliative care and only 9% had accessed SPC services for advice. Leadership is not enough. Clear leadership requires knowledge and experience.

Kitson et al (1998) identifies an effective organisational structure as the second element of leadership. The provision of such an organisational structure is challenging in the care home context; and, if there is a transient management team, bringing about change may not be possible. Care homes are care giving organisations, whose primary task is to provide care (Khan 2005). The role of leaders in such care giving organisations is complex because as well as undertaking the usual leadership role, there is an additional relational role that needs to be taken account of. To achieve this, development of supportive relationships are crucial between these care giving organisations with those who are seeking care (Khan 2005). Khan (2005) stresses that leaders in such organisations have to enable their staff to remain resilient, even in

times of stress and anxiety. Support for staff in providing care would indicate that the organisation has an effective organisational structure.

The third element of leadership identified by Kitson et al (1998) is effective team work. In a small exploratory study, Wicke et al (2004) reported that whilst care home nurses wished for good teamwork, the culture of hierarchical management in a profit making organisation made this difficult to achieve. The RCN (2011) reported that developing teamwork was challenging with an increasingly transient workforce in care homes. A survey undertaken in 2004 highlighted that four percent of respondents had worked in their current workplace for less than one year; by 2011 this had risen to 26% of respondents (RCN 2011). Due to staff turnover there was little opportunity to foster teamwork in day to day activities, with work being task focused. Group and team meetings were absent.

This emphasises the specific challenges that care homes experience when implementing any change, and especially cultural change in relation to end-of-life care. Historically, care homes have been isolated from new developments in palliative care (Gibbs 1995). Many care homes are private businesses and are not part of the National Health Service. They have traditionally been seen as insular private companies that are in competition with other local care homes (Forder and Allan 2011). Owen et al (2012) report that care home managers feel isolated from the wider social and healthcare system. This means that whilst they are part of a wider system, they may have a limited, or indeed no, relationship between themselves and the other constituent parts of the system (Knight et al 2008). Partnership working, cooperation

and collaboration between care homes, rather than being in competition may help change to occur and indeed for change to be sustained (Owen et al 2012).

The final element of leadership identified by Kitson et al (1998) is clear roles. Care home staff tend to have clear roles; however, with the element of effective team work missing, subcultures are created which act as a barrier to change (see 3.1). To aid change it would seem clear roles need to be linked with an understanding and appreciation of other's roles in the change process which potentiates good teamwork.

3.4.3: Measurement and change in care homes

Change should result in measurable outcomes and be in line with the organisation's vision. This can only occur if outcome measures are in place at the outset. Evidence enables those instigating and implementing the change to see value in what they are trying to achieve. This was initially referred to as measurement by Kitson et al (1998) but subsequently changed to evaluation by McCormack et al (2002).

When collecting evidence of change, Senge et al (1999) cautioned organisations about reliance on only quantitative data. However in a cost driven market, where commissioners' funding of a service is increasingly based on evaluation of performance outcomes the use of other measures may not be sufficient. In care homes the collection of mandatory information for the Care Quality Commission, their regulator, and for the care home owners, is continuous, at least once a year (Care Quality Commission 2013b). Documented evidence of quantitative data such as staff undergoing mandatory training and supervision sessions is essential. Audit and feedback to staff tend to occur when standards have not been met, due to the

repercussions. However, with respect to end-of-life care such evaluations may now encompass observation of staff communication and interaction with residents and their family (Care Quality Commission 2013c). The onus remains on performance. In an attempt to gain more detail of the end-of-life care actually provided by a service and to support the implementation of their End-of-life Care Strategy, quality markers and measures for end-of-life care were published by the Department of Health (2009). However, its implementation is neither financed, nor mandatory, and so its value may be limited.

McCormack et al (2002) recognises nursing care homes as having narrow sources of performance information, single evaluation methods and an absence of feedback. As a result, they highlight that the evaluation provided by care home organisations is weak. Twelve years on, end-of-life care training is still not mandatory, and, its provision and quality of training are not specifically regulated. However, external regulation of the care homes now incorporates mechanisms for feedback from residents and their families. This now offers one means to evaluate care, including the care provided at the end-of-life.

When considering the implementation of new knowledge into care home practice the context which incorporates culture, leadership roles and how systems and services are routinely monitored in the organisation (Kitson et al 1998) do need to be taken account of. The final component of Kitson et al (1998) conceptual framework, alongside the context of care homes and the evidence of the change initiative, is that of how the change is facilitated. This is now discussed.

3.5: Facilitation in relation to change

Within the literature, a common description of facilitation is ‘to make easier’. Terms for facilitation in the literature vary but incorporate diversity, and included: ‘high’ and ‘low’ facilitation (Kitson et al 1998); ‘basic’ and ‘developmental’ facilitation (Schwarz 2002); and, ‘task’ and ‘holistic’ facilitation (Harvey et al 2002). What is clear from the review of the literature is that the purpose of facilitation varies, from enabling organisation-wide holistic change initiative to facilitating a single discrete task-orientated activity (Harvey et al 2002). To understand the contribution of facilitation when implementing change, three important considerations were identified: the role of a facilitator; their characteristics; and, their style (Kitson et al 1998).

3.5.1: The facilitator’s role and characteristics

Where a detailed description of a facilitator’s role is provided, the ability of a facilitator to help others learn is central to the definition. Definitions include that provided by Heron (1989:11) who states a facilitator:

‘is a person who has the role of helping participants to learn in an experimental group....by experimental group I mean one in which learning takes place through active and aware involvement of the whole person.’

The need for learning, that Heron (1989) made reference to, is also evident in the description of the facilitator’s role provided by Kitson et al’s (1998), namely:

- to understand what needs to be changed
- to understand how to change it
- to know, verbalise and ensure understanding of the intended outcome

- to help those they are facilitating, understand how to achieve the desired outcome

To achieve this, learning by the facilitator as well as by the participants needs to occur.

Kitson et al (1998) therefore propose that because of the relatively low care home context, facilitating the implementation of research or change into such an environment requires high not low facilitation. High facilitation is defined by a facilitator successfully negotiating the change agenda who has authority, or access to authority, to implement change. Such a facilitator has respect, empathy, authenticity and credibility characteristics (Kitson et al 1998).

Harvey et al (2002:581) describes a facilitator's role as being: 'concerned with enabling and the development of reflective learning by helping to identify learner needs, guide group processes, encourage critical thinking, and assess the achievement of learning goals'. It could be assumed from Harvey et al's (2002) description that a facilitator would have the appropriate skills and knowledge to enable learning in the individual, group or organisations with whom they are working. Facilitation is described by Seers et al (2012:2) as:

'a mechanism or intervention for the implementation of evidence into practice....it involves the facilitator working with individuals, teams, and organisations to prepare, guide and support them through the implementation process.'

Seers et al (2012) recognised such a role to be complex and multifaceted.

3.5.2: Facilitation styles and purpose

Harvey et al (2002) believed that facilitation should be provided by an individual, internal and/or external to the organisation, who had been appointed to provide this role. Such a role should always be one of enabling, not telling. Although the style of facilitation might vary, what is important is that it matches the task in hand, or the type of change being undertaken, in order to fulfil the role effectively (Harvey et al 2002). The task in hand may range from a specific task focused change through to cultural change at an organisational level. A task orientated, doing-for role, means the facilitator style could be episodic, didactic and provide direct practical or teaching help. Kitson et al (1998) refers to this as a low facilitation style. However, if the change to be undertaken is one of cultural change at an organisational level the facilitation would need to be high, using a holistic, enabling approach. The facilitator's style for this would need to be flexible and vary according to need. In addition, there would need to be a constant presence in the organisation, giving appropriate and consistent support (Kitson et al 1998). Cultural change has been identified to require a longer period of facilitated help. Such a facilitation style requires: critical reflection skills; co-counselling; flexibility; and to be able to give meaning, realness and authenticity (Harvey et al 2002). Heron (1989) suggests that an additional consideration should be the stage of implementation of change. Depending upon the context, early in the process the facilitation style would be more hierarchical and in the later stages, more self-directed.

Harvey et al (2002) states that to be effective, facilitators need to be able to: adapt their style according to the context and purpose (type of change). However, this is dependent on the skill and knowledge of the individual. In any role, experience is

gained in practice whilst undertaking the role, which offers the opportunity for learning over time (Benner 1984). Harvey (in Harvey et al, 2002:582) suggests this to be the case with the role of a facilitator: as facilitation experience is gained, the facilitator style changes. The format of facilitation offered alters from a low facilitation model (doing for) to that of the high facilitation model of 'enabling' and role modelling. If this is so, it would suggest that experience, as well as an individual facilitator's attributes will impact on the style of facilitation that is provided, regardless of the type of change that they are actually facilitating. However, this may not be the case. A facilitator may gain experience in terms of time spent, but this does not necessarily equate with learning different facilitation styles. Time spent in the role may simply lead to experience accumulating one style of facilitation, especially if the evidence and context where they work, supports this model. Auvine et al (2002) made the interesting comment that the facilitator needs to recognise that they should learn from the participants as well as vice versa. This again suggests that facilitator's develop the learning styles they provide.

Although Harvey et al (2002) recommend that a facilitator's style should match the change process that is planned, there is little within the literature, that specifies standards by which the competency of a facilitator is to be assessed or developed (Auvine et al 2002). Whilst not specific to care homes, in 2012 the National End of Life care programme published the End-of-life Care Facilitator Competency Framework. In the current financial climate where facilitation is funded, the outcome of providing facilitation may need to be measured. The National End of Life care programme (2012) competency document may be helpful as one of its competency sections encourages audit.

3.6: Conclusion

Initiating or implementing organisational change is undoubtedly challenging especially in care homes which have been identified to have a weak context. Kitson et al (1998) propose that high facilitation is one way of counteracting a weak context when bringing about change. What is important is ensuring that the help required is made available. Otherwise, participants' learning capabilities will not be developed and the change initiative is likely to fail (Senge et al 1999). Soft Systems Methodology provides a framework to identify and understand the context when a change is to be initiated. Such knowledge needs to be taken into consideration when a plan of implementation is made.

It has been discussed that culture can be practice and/or learning based. It is in those organisations that are not only willing to learn, but also develop an ongoing commitment to learn, where change has the potential to be sustainable and remain ongoing. This enables sustained cultural change and it is therefore how culture is defined for the purpose of this study. The literature reviewed in relation to facilitation, suggests that care homes and their external system, including their facilitator, need to learn together for such change to occur.

In the next chapter, a systematic literature review is undertaken investigating the quality of evidence supporting the implementing of end-of-life care initiatives into nursing care homes. As previously acknowledged, Shaw et al (2010) undertook a critical review of the GSF in primary care. There was no evidence of this having been undertaken in relation to the GSFCH Programme. As this thesis is focused on the GSFCH programme, establishing the evidence base of the outcomes and process of

implementation through a systematic review of the existing literature was essential. It would enable existing knowledge, including knowledge of facilitation of the GSFCH programme, to be utilised to shape the design of the study and then be developed within this study. Two separate reviews were therefore undertaken to determine firstly, the quality of evidence supporting the implementation of the GSFCH programme in relation to outcomes and secondly, what enabled the change to occur. Looking at the evidence from the systematic reviews, in relation to the care home context may reveal a clearer picture of the role of facilitation in this process (Kitson et al 2008).

Chapter Four – Implementation of end-of-life care interventions: the supportive evidence

Achieving organisational change in care homes is complex and challenging. The contributions of context and facilitation to this process have already been considered. However, when implementing organisational change a third element, that of the evidence supporting the change initiative, is also important (Kitson et al 1998 and Rycroft-Malone et al 2003). Evidence relates not only to the quantity of the information that is available but also, its quality. If the quality of the evidence about an intervention is an important factor to consider before implementing the intervention into practice, then the evidence supporting the GSFCH programme needed to be established (Kitson et al 1998). Therefore, although the GSFCH, the LCP/ICP and education and/or training were previously defined, the evidence supporting the implementation of these three end-of-life care interventions into practice is now examined.

It was important to identify all evidence relating to the programme. The intention was to understand the process of implementing the GSFCH Programme. However, if in fact the evidence on outcomes did not support the programmes implementation, then undertaking a study examining how best to do this would not be justifiable. The preceding chapter identified the challenges of initiating a change process and that the change should be supported by, and understood in relation to, the evidence available. This was achieved by undertaking two systematic reviews looking at evidence of:

- outcomes resulting from the implementation of the interventions
- the process of bringing about change

These two systematic reviews are reported within this chapter. The first systematic review was undertaken in 2010 (Kinley et al 2013a) and the searches used in 2010 re-run in 2013; no additional articles or reports were identified. A summary of this is provided. The second review was undertaken in 2013.

4.1: Evidence of the outcomes from implementing an end-of-life care intervention

In 2006, Froggatt et al (2006) reviewed the literature on end-of-life care in long term care settings for older people. The review identified 25 papers addressing modes of service delivery but they mainly reported small-scale descriptive accounts of interventions and developments. A few years later, (Hall et al 2011a) undertook a Cochrane review to determine the effectiveness of multi-component palliative care service delivery for older people, living in nursing care homes. Only three studies were identified (two RCTs and one controlled before-and-after study), all of which were undertaken in the USA. There were few resident outcomes. Reported outcomes included residents with end-stage dementia having lower observed discomfort; higher satisfaction with care; higher referrals to hospice services; fewer days in hospital and hospital admissions and, an increase in the documentation of advance care planning discussions, including decisions concerning resuscitation status.

No systematic literature review had been undertaken that considered the impact of the UK policy recommendations on the provision of end-of-life care within the nursing care home setting. A systematic review was therefore undertaken, to establish the evidence base as it currently stood (Kinley et al 2013a).

4.1.1: The research question and aim of the systematic review on outcomes

The systematic review aimed to answer the following question:

What is the effect of policy on end-of-life care practice within UK nursing care homes?

The review aimed to identify the impact of implementing end-of-life care policy, with regard to the use of the GSFCH programme, the LCP (or the Integrated Care Pathway² (ICP) for the last days of life in care homes). It also considered education and/or training interventions used to support the provision of end-of-life care, within a UK nursing care home context.

4.1.2: Search strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist (PRISMA) was used to guide the systematic review and its subsequent publication (Kinley et al 2013a). A copy of the paper is enclosed in Appendix Two. The GSF was developed in 2000 and the LCP in 2001, so Medline, CINAHL, EMBASE, Web of Science and the Cochrane library were searched, for publications reporting the implementation of the GSFCH, LCP/ICP or a end-of-life care or palliative care educational and/or training initiative between 2000 and April 2013. Websites of government and palliative care organisations were also searched. The review focus was on nursing care homes and so only papers reporting on adult UK nursing care home residents, their relatives and the staff working within these nursing care homes were included. This decision was made because the resident population in nursing care homes and residential care homes, that provide only personal care, vary

² Within this literature review all subsequent references to an ICP relate specifically to the use of an ICP for the last days of life in care homes

substantially, so does the need for care and thus care provision. During the period under review, implementation of these tools was mainly within nursing care homes. Participants from dual-registered homes (providing beds with and without nursing care) were included as long as details pertaining to the nursing care home residents could be extrapolated, or where the majority of the sample was nursing care home residents. Finally, only UK-based studies/reports written in the English language were included.

4.1.3: Results

Eight papers/reports, incorporating information from three studies, were identified. No study reporting on the implementation of an end-of-life care education and/or training intervention, actually met the inclusion criteria. They were all non-analytical case series studies³ and so provide Grade D evidence for practice⁴ (Scottish Intercollegiate Guideline Network 2008).

Two studies reported the implementation of the GSFCH programme whilst a third reported on the implementation of an ICP for the last days of life in care homes. Where present, data were extracted on outcomes related to the resident, the family and the staff in all three studies.

The systematic review provided limited evidence on improved outcomes following the implementation of the GSFCH programme and the ICP for the last days of life and concluded that ongoing research is needed both within the UK and internationally to

³ Hierarchy of evidence ranging from Grade 1 which includes RCT to Grade 4 which refers to evidence arising from expert opinion.

⁴ Ranges from A–D where D represents the lowest grade in terms of recommendation for practice.

measure the impact of these initiatives on end-of-life care outcomes, within nursing care homes (Kinley et al 2013a). In relation to end-of-life care within nursing care homes within the UK, there is currently a lack of outcome evidence regarding the value of education and/or training on actual practice and therefore its use as a singular initiative is questionable. This systematic review raised questions about what supported the development of end-of-life care in nursing care homes in the UK.

4.2: Evidence supporting the process of implementing an end-of-life care intervention

The initial systematic review did not answer questions about the process of bringing about change. A second systematic review was therefore undertaken. Again the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist (PRISMA) was used to guide the systematic review (Appendix Three).

4.2.1: The research question, aim and objectives of the systematic review on process

This systematic review aimed to identify what was known about the process of implementing an end-of-life care intervention in a nursing care home. It asked the following research question:

What is known about the process of initiating, implementing, and then sustaining, the GSFCH programme, the LCP/ICP, and educational and/or training interventions within nursing care homes, to support the provision of end-of-life care?

The objectives of this review were:

1. To identify studies reporting on the implementation of the GSFCH programme, the LCP/ICP and educational and/or training interventions within nursing care home settings to support the provision of end-of-life care.
2. To identify the factors that enabled and hindered the implementation of these interventions into nursing care home practice.
3. To identify evidence of how sustainability of the intervention had been considered beyond the Implementation Phase or the project time.

4.2.2: Search strategy

As the GSF was developed in 2000 and the LCP in 2001, Medline, CINAHL, EMBASE, Web of Science and the Cochrane library were searched, for papers and reports published reporting on the implementation of the GSFCH, LCP/ICP or a end-of-life care educational and/or training initiative between 2000 and 27th April 2013. Where possible, the following a thesaurus/subject heading and free text search terms were used in each of the databases listed above - nursing home* **OR** residential home* **OR** care home* **OR** aged care facilit* **OR** long-term care **AND** end-of-life **OR** hospice* **OR** terminally ill **OR** terminal care **OR** hospice care **OR** palliative care. Where possible the search was then limited to age groups aged 65 or more years and/or aged 80 years or more and to articles written in English.

The search result obtained from the detailed search listed above was then combined with **AND** in association with each of the following searches:

- GSF or Gold Standards Framework or GSFCH or Gold Standards Framework in Care Homes **OR**

- Integrated care pathway or ICP or Liverpool Care Pathway or LCP **OR**
- Education or training

In addition a web site search was undertaken on:

- <http://www.goldstandardsframework.nhs.uk/>
- <http://www.mcpcil.org.uk/index.htm>

Resources listed on these web sites in relation to end-of-life care and care homes were reviewed and studies and reports were incorporated into this review, if they met the inclusion criteria.

The reference lists of studies that were retrieved for the detailed evaluation were hand-searched, for any additional relevant citations. Once retrieved, each additional article was reviewed before accepting it into the review, or rejecting it. Whilst specific journals and the grey literature were not hand-searched, the final list of retrieved articles was sent to three experts alongside the inclusion and exclusion criteria, to ensure there had been no omissions.

Inclusion and exclusion criteria

Studies were included within the review if they met the inclusion criteria specified in Table 4.1.

Table 4.1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • All/the majority of the study sample were nursing care home residents, their relatives and/or staff 	<ul style="list-style-type: none"> • All/the majority of the study sample were working in/associated with care homes providing personal care • All/the majority of the study were young people with a physical disability or learning difficulties
<ul style="list-style-type: none"> • The staff has either: <ul style="list-style-type: none"> ○ attended the GSFCH programme ○ implemented the LCP/ICP ○ attended an end-of-life care event where the aim was to improve knowledge, skills and/or behaviour 	<ul style="list-style-type: none"> • Intervention was not the LCP/ICP, GSFCH or an end-of-life care education and/or training event
<ul style="list-style-type: none"> • Was either a Randomised Controlled Trial, Meta-analysis, systematic review, observational study (before-after/cohort study/cross-sectional/case control study), or a non-comparative study (case-series/case report) 	<ul style="list-style-type: none"> • Grey literature
<ul style="list-style-type: none"> • English Language 	<ul style="list-style-type: none"> • Not published in English
<ul style="list-style-type: none"> • Published between 2000-2013 	

4.2.3: Data Extraction

For each study that met the inclusion criteria, the following details were obtained:

- study design
- level of evidence/recommendation for practice
- universal factors that influenced the decision to implement the intervention
- details of the implementation of each intervention
 - the target of the intervention for learning
 - at an individual level
 - at an organisational level – to staff with varying roles within one nursing care home
 - at a role specific level - to a group of staff with a particular role

- the study sites and participants
- details of the ‘change agent’ - those implementing the intervention
- reported factors that enabled the interventions to be implemented

4.2.4: Results:

Fifty-five articles containing information arising from the implementation of 36 interventions fully met the inclusion criteria for the process review (Figure 4.1).

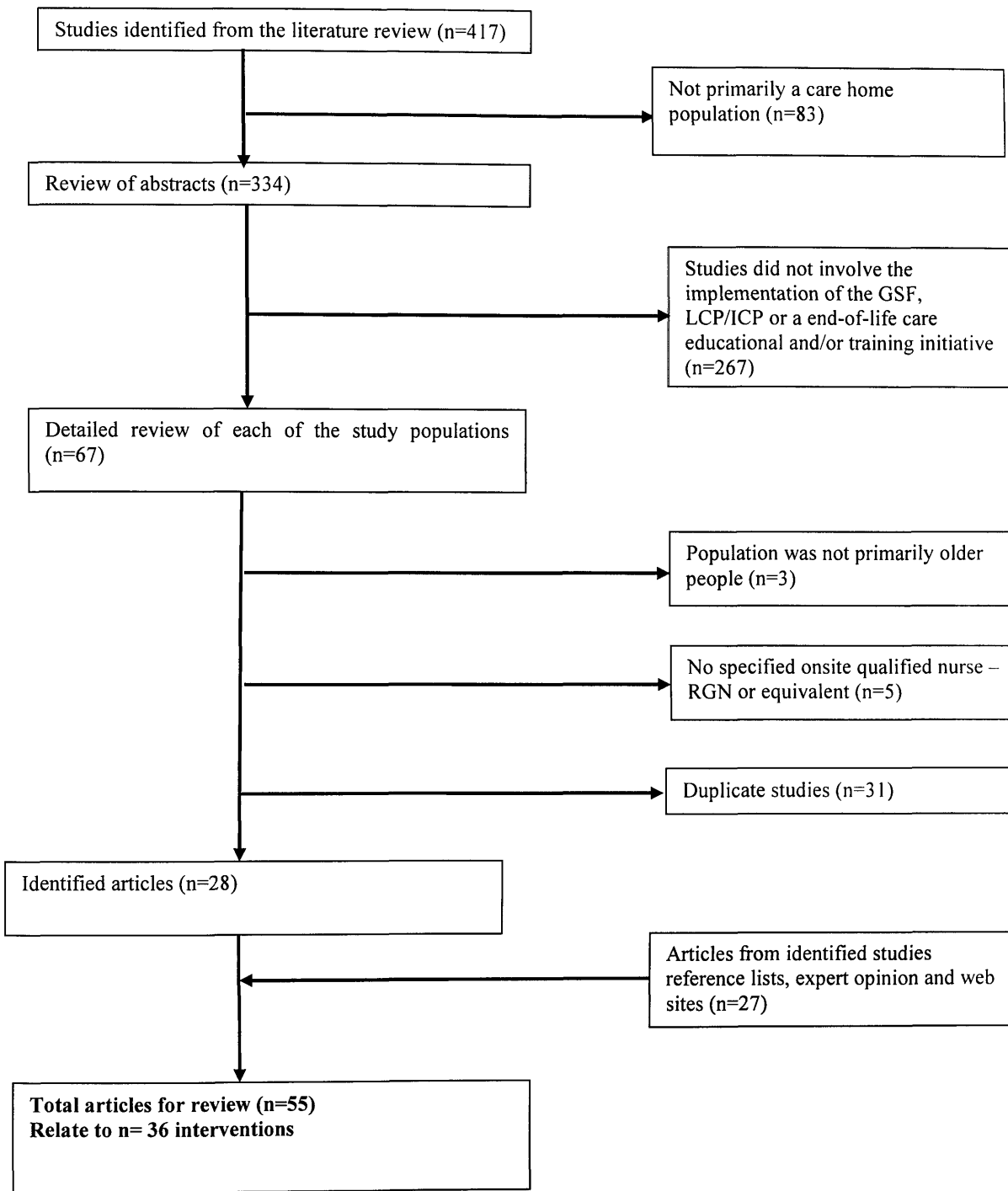


Figure 4.1: The review process

Of the 55 articles:

- Seven⁵ studies (14 articles) reported the implementation of the GSFCH intervention
- Seven⁵ studies (12 articles) reported the implementation of the LCP/ICP for the last days of life intervention
- Twenty-three studies (31 articles) reported the implementation of an education and/or training intervention.

4.2.5: Study design and level of evidence

No meta-analysis, systematic reviews or case control studies were identified. Nine studies were before and after observational studies (Ersek et al 2005, Waldron et al 2008/Hasson et al 2009, Ersek et al 2006, Hanson et al 2005, Parkes et al 2005, Wen et al 2005, Keay et al 2000/Kray et al 2003, Hockley et al 2004/5/Dewar and Sharp 2006/Watson et al 2006 and Reymond et al 2011). These and all remaining studies, which were non-analytical, were categorised as providing Level 3 evidence using the Scottish Intercollegiate Guideline Network (2008) grading system. They were graded D in terms of recommendation for practice. The CRCT (Hockley et al 2012a) provided insufficient detail to be graded. The author was contacted and the study graded as Level 1.

⁵ One study (2 articles) provided data arising from the implementation of the LCP and the implementation of the GSFCH intervention – so incorporated as +1 study and +2 articles into both the LCP/ICP and GSFCH sections above. Information from this study is incorporated into the LCP/ICP review and the GSFCH review accordingly

4.2.6: The decision to implement the intervention

There were a number of universal factors reported that influenced the decision to implement the intervention. Twelve studies acknowledged that the ageing global population meant ensuring end-of-life care was developed and provided well was an important investment for the future. Twenty-six studies referred to the increasing role that nursing care homes have and will have in providing end-of-life care for this population. Whilst it was recognised that SPC should guide this process, translation of their knowledge before its transference into another field of practice needed to occur. Such translation was recommended within eight studies. Thirteen studies highlighted the need for services to work together. Three studies implementing the GSFCH programme and three implementing the LCP/ICP acknowledged that implementation of these interventions was a national recommendation.

4.3: Implementation of the interventions

The implementation of the three interventions, namely: the GSFCH programme, the LCP/ICP and education and/or training to support the provision of end-of-life care, are now described in turn. Following this the key findings and implications for practice are then collectively reported.

4.3.1: Implementation of the GSFCH programme

Within the seven studies identified (Table 4.2 and 4.3), there were substantial differences both in the method and intent of the implementation of the GSFCH intervention. The seven studies took place from the initial concept of the GSFCH programme in 2004 (*Phase 1*) to its more recent format in 2009 (*Phase 6*).

The first study reporting on the implementation of the GSF was Thomas et al (2005). Prior to this, the GSF had only been used within primary care. The focus of this study was to determine the important components to incorporate from the primary care GSF experience when implementing the intervention within a nursing care home setting.

The six subsequent studies reported on the GSFCH implementation when the intervention's core components had been identified. The number of workshop days had been increased to four. The workshops included education, implementation of the LCP or equivalent, reflective practice and project work (Table 4.2). Clifford et al (2007) study was undertaken with nursing care homes participating in the earlier phase of the GSFCH programme '*Phase 2*'. The study by Hockley et al (2012a) was undertaken four years later with nursing care homes participating in the GSFCH programme '*Phase 6*' (see 2.6.1).

The target for learning within these seven studies varied but all incorporated organisational and/or role specific learning. The implementation of the GSFCH programme resulted in evidence of change in practice in all but two studies (Table 4.3).

Table 4.2: Format of the GSFCH interventions

Intervention	Reported format of intervention						
	Education	Provision of written resource/s	Use of scenarios	Developed in-house policy to guide practice	Reflection/story telling	Placements	Project work
Thomas et al (2005)	Yes	Yes		Yes	Yes		Yes
Badger et al (2009/12) Clifford et al (2007) Hewison et al (2009)	Yes	Yes			Yes		Yes
Seymour and Froggatt (2009) Seymour et al (2010)	Yes	Yes			Yes		Yes
Hall et al (2011b)	Yes	Yes			Yes		Yes
McClelland et al (2008) Ashton et al (2009)	Yes	Yes	Yes		Yes		Yes
Hockley et al (2008/10) Watson et al (2010)	Yes	Yes	Yes		Yes		Yes
Hockley et al (2012a)	Yes	Yes			Yes		Yes


Key: no evidence 

Table 4.3: GSFCH interventions

Study Country	Phase of GSFCH programme (where Phase 1 is the pilot and the phase increases sequentially for each year it is run)	Participant details		Study sample	Number of nursing care homes	Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Study sample	Participant details						
Thomas et al (2005) England	Phase 1 (pilot)	n=not given but all staff involved	n=12	O+RS	Yes	No	Nine months No	No	
Badger et al (2009) Clifford et al (2007) Hewison et al (2009) Badger et al. (2012) England	Phase 2	n=not given (case series evaluation) n=14 managers n=26 RGNs* n=30 HCAs** n=4 domestic staff n=1 primary care Liaison Nurse n=7 residents n=3 relatives	n=44 for those with pre and post data on deaths (of these n=10 case study homes)	O+RS	Yes	No	One year No	No	
Seymour and Froggatt (2009) Seymour et al (2010) England	Phase 2	n=not given but all staff involved	n=1	O+RS	No	No	15 months Yes-evaluated 2007/08 GSFCH programme started 2005.	Yes-manager attended six weekly PCT palliative care strategy meetings. Syringe driver library established.	
Hall et al (2011b) England	Phases 2,3,4	n=8 RGN n=9 HCAs n=9 managers n=11 residents n=7 family members	n=9	O	No	No	Not given No	No	
McClelland et al (2008) Ashton et al (2009) England	Phase 3	n=200 'pre' survey and n=173 'post' n=16 HCA interviews n=13 focus groups all staff n=4 family members n=22 GPs/OOH GP	n=5 (4 nursing care homes and 1 NHS mental Health Ward)	O+RS	Yes	No	One year No	No	

Study Country	Phase of GSFCH programme (where Phase 1 is the pilot and the phase increases sequentially for each year it is run)	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participant details	Number of nursing care homes				
Hockley et al (2008/10) Watson et al (2010) Scotland	Phase 4	n=not given but all staff involved n=36 bereaved relatives included	n=7	O+RS	Yes	18 months No	No
Hockley et al (2012a) England	Phase 6	n=12 nurse managers	n=38	RS	Yes	Nine months No	No

*RGN = Trained nurses

** HCAs = Health Care Assistants (HCAs) or equivalent

4.3.2: Implementation of the LCP/ICP for the last days of life

Nursing care homes either implemented the LCP or the ICP for the last days of life. Mathews and Finch (2006) and Duffy and Woodland (2006) reported implementation of the LCP as a pilot study. Following registration with the national LCP project in Liverpool, the nursing care home utilised the documentation the national team supplied, when implementing their intervention. The participating nursing care homes in Seymour and Froggatt (2009), Seymour et al (2010) and Mathews and Finch (2006) studies also used the national LCP documentation.

Jones and Johnstone's (2004), Reymond et al's (2011), Knight et al's (2007/8) and Hockley et al's (2004) studies introduced an ICP rather than the LCP, so the participating nursing care homes did not need to register with the national Liverpool Care Pathway project. The ICP utilised by Hockley et al (2004) had been adapted, formatted and piloted, by all levels of staff (internal and external), within other nursing care homes prior to this study. Whilst Reymond et al (2011) described the ICP development, Jones and Johnstone (2004) did not provide details on how the format of the modified ICP they used was decided.

Within the implementation, all studies included education, the provision of written materials and were able to evidence change in practice through audit (Table 4.4). The focus for learning varied. Learning was either targeted at an individual practitioner level, or targeted at staff across the whole nursing care home, or focused specifically on the role held such as the nursing care home managers. These seven studies all incorporated both organisational learning and learning that was undertaken in groups,

such as a group of health care assistants, referred to as role specific learning (Table 4.5).

Table 4.4: Format of the LCP/ICP interventions

Intervention	Reported format of intervention							Project work
	Education	Provision of written resource/s	Use of scenarios	Developed in-house policy to guide practice	Reflection/story telling	Placements		
Jones and Johnstone (2004)	Yes	Yes	Yes	Yes				
Hockley et al (2004/5)	Yes	Yes			Yes			
Dewar and Sharp (2006)								
Watson et al (2006)								
Duffy and Woodland (2006)	Yes	Yes			Yes			
Mathews and Finch (2006)	Yes	Yes		Yes				
Knight and Jordon (2007)	Yes	Yes		Yes	Yes			
Knight et al (2008)								
Seymour and Froggatt (2009)	Yes	Yes						
Seymour et al (2010)								
Reymond et al (2011)	Yes	Yes						

Key: no evidence

Table 4.5: LCP/ICP interventions

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participant details	Number of nursing care homes				
Jones and Johnstone (2004) Wales	ICP	n=not given	n=25	O+RS	Yes	One year No	No
Hockley et al (2004/5) Dewar and Sharp (2006) Watson et al (2006) Scotland	ICP	n=not given	n=8	O+RS	Yes	One year No	No
Duffy and Woodland (2006) England	LCP	n=not given	n=1	O+RS	Yes	Two years Yes -audit after six months implementation	No
Mathews and Finch (2006) England	LCP	n=not given	n=1	I+O+RS	Yes	Not given No	No
Knight and Jordon (2007) Knight et al (2008) Wales	ICP	n=not given	n=29	O+RS	Yes	Three years Yes -audit one year after implementation	No
Seymour and Froggatt (2009) and Seymour et al (2010) England	LCP	n=not given but all staff involved	n=1	O+RS	Yes	One year Yes -evaluation one year later	Yes -staff attend syringe driver training three monthly
Reymond et al (2011) Australia	ICP	n=514	n=6	O+RS	Yes	One year and nine months No	None

4.3.3: Implementation of education and/or training to support the provision of end-of-life care

Within the 23 identified studies (Table 4.6) there were four distinct approaches taken when implementing an end-of-life care education and/or training course for nursing care home staff. These included:

- providing a study day/a series of study days
- education of link nurses
- use of reflective learning
- multimodal interventions.

Table 4.6 illustrates the similarities and differences in the format of each approach.

The first approach (seven studies) involved learning through education/practice development sessions alone (Table 4.6). Six studies implemented the training sessions over a period of time. Within one study the duration of the intervention was determined according to nursing care home staff roles; RGNs had a 12 day course; HCAs a seven day course and ancillary staff a one day course (Froggatt 2000a/b). The RGNs and HCAs attended weekly sessions, with their final day being a follow up day three months later. By contrast, Dowding and Homer (2000) held a one day training event, described as a ‘pilot’ study day for HCAs, with no follow up opportunity provided. Whilst evidence was provided within eight studies, that learning through education and/or practice development sessions changed practice, this did not occur in any intervention providing study day/a series of study days alone (Table 4.7).

Table 4.6: Format of the education and/or training interventions to support the provision of end-of-life care

Intervention	Type of Intervention	Reported format of intervention						Project work
		Education	Provision of written resource/s	Use of scenarios	Developed in-house policy to guide practice	Reflection/ story telling	Placements	
Froggatt (2000a/b)	Series of study days	Yes						
Curry et al (2009)		Yes	Yes	Yes		Yes	Yes	Yes
Moran (2009)		Yes		Yes		Yes		
Dowling and Homer (2000)		Yes				Yes		
Wen et al (2012)		Yes						
Parks et al (2004)	Education of link nurses	Yes	Yes					
Ersek et al (2005)		Yes	Yes	Yes				
Heals (2008)		Yes	Yes				Yes	
Partington et al (2008)		Yes				Yes		
Ersek et al (2006)		Yes	Yes					Yes
Kortes-Miller et al (2007a/b)		Yes	Yes			Yes		
Kelly M (2008)		Yes	Yes					
Waldron et al (2008)		Yes	Yes	Yes				Yes
Hasson et al (2008)		Yes	Yes			Yes		
Cheetham (2008)		Yes	Yes					
Kelly et al (2008)	Reflective learning Multimodal intervention	Yes	Yes	Yes				Yes
Kelly et al (2011)		Yes	Yes			Yes		Yes
Hewison et al (2011)		Yes	Yes			Yes		Yes
Hockley and Froggatt (2006/11)		Yes	Yes		Yes	Yes		Yes
Kuhn and Forrest (2012)		Yes	Yes		Yes	Yes		Yes
Raunkiae and Timm (2010)		Yes			Yes	Yes		Yes
Braun and Zir (2005)		Yes		Yes	Yes	Yes		
Keay et al (2000/3)		Yes	Yes				Yes	
Hanson et al (2005)		Yes	Yes		Yes			Yes
Penrod et al (2007)		Yes			Yes			
Hill et al (2005)		Yes	Yes	Yes	Yes	Yes		Yes

Key: no evidence

Table 4.7: Education and/or training interventions to support the provision of end-of-life care

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participants	Number of nursing care homes				
Froggatt (2000a/b) Froggatt et al (2000) England	Evaluated a pilot educational course.	n=151 RGNs n=115 HCAs n=75 Ancillary staff	n=54	O+RS	No	Two years No	No
Curry et al (2009) Ireland	Education programme using a practice development framework.	n=3 RGNs n=4 HCAs	n=2	O	No	10 months Yes-focus group four months after implementation	No
Moran (2009) Ireland	A service improvement programme. Provided two education days and monthly practice development and support meetings.	n=not given but all staff involved	n=1	I+O	No	Six months No	No
Dowding and Homer (2000) England	A study day for HCAs.	n=3 RGNs n=41 HCAs	n=not given	I+RS	No	One day No	No
Wen et al (2012) Hawaii	A quality improvement education intervention. Six monthly lecturers provided.	n=124 (RGNs, CNAs, LPNs and ancillary staff)	n=5	I	No	Six months No	No
Parke et al (2005) USA	Pilot. Five in-service lecturers focused on end-of-life care for dementia residents.	n=29 ancillary staff (included CNAs, social workers, recreational therapists and food service workers)	n=1	I+O	No	Eight weeks Yes-questionnaire before and after one year – attitudes and knowledge.	No

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participants	Number of nursing care homes				
Ersek et al (2005) USA	Development and evaluation of a palliative care education team.	n=108 RGNs n=61 HCAs	n=44	O	No	Four months Yes-after six months survey of participants and assessment by supervisor.	No
Heals (2008) England	Palliative care link nurse programme. Link nurse network and four study days and newsletters a year.	n=64 RGNs	n=32	I+RS	No	Four years Yes-evaluation after one year – no comparative data. Individual benefit. No evidence of cascading knowledge.	Yes-running for four years
Partington et al (2008) England	Palliative care link nurse programme.	n=78 RGNs	n=not given (Area 1) n=31 (Area 2)	I+RS	No	Area 1 – four years Area 2 – unknown Yes-in Area 1 meetings and newsletter three times a year	Yes-still running four years later in Area 1 only
Ersek et al (2006) USA	Train the Trainer programme in which educators who then ran in-service educational sessions in their own homes.	n=87 participants (n=73 from nursing care home) some held more than one position With the train the trainer model almost 2,000 nursing care home staff received education in at least one topic	n=45	O	Yes	Six months No	No

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participants	Number of nursing care homes				
Kortes-Miller et al (2007a/b) Kelley (2008) Ontario	A 15 hour Interprofessional curriculum for rural long-term care settings. Training delivered by a member of care home staff who was externally supported.	n=5-19 staff in each locality	n=3	I+O	No	Two days- six weeks No	No
Waldron et al (2008) Hasson et al (2008) Ireland	In house teaching was provided to link nurses, who in turn could deliver training to other staff.	n=30 RGNs	n=33	I+O+RS	No	Three years No	No
Cheetham (2008) England	Provided practical training in the nursing home. Established a link nurse or senior carer.	n=not given but all staff involved	n=not given	O+RS	No	No time frame Yes-states the link nurse attends local area meetings and maintains resource file	No Yes-link nurse attends local meetings. No further details given
Kelly et al (2008/11) USA	Pilot train the trainer model to disseminate palliative care education in geriatric setting. Two day conference, given information on nine modules to them run in own area.	n=76 participants (7RGNs, 2 CNS, 6 nurse practitioners, 16 care coordinators, 9 managers, 23 directors, 6educators, 2chaplains, 5 social workers and 1 not reported)	n=not given	I+O+RS	No	Three years Yes-survey at one, four and 12 months. Reported implementation of intervention.	No
Hewison et al (2011) England	Action learning for nursing care home managers.	n=10 RGNs	n=8	I+RS	Yes	Eight months	No
Hockley and Froggatt (2006/11) England	Critical action research study.	n=not given but all staff involved	n=2	O	Yes	No Five years No	No

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participants	Number of nursing care homes				
Kuhn and Forrest (2012) USA	Pilot project in nursing care homes with dementia residents involving six training modules, care consultations and administrative coaching.	n=80 staff (nurse=8.2%, HCA=33.3%, other= 39.5%) n=31 residents n=33 family members	n=2	I+O	No	One year Yes-six and 12 months post training in one of the two homes with stable leadership. Chart review and family and staff questionnaire.	No
Raunkiaie and Timm (2010) Denmark	To develop palliative care competencies through three pedagogical methods (education, professional guidance and local development projects)	n=129 Education n=41 Professional guidance n=11 Project development n=3 university guides	n=3	I+O	Yes	Three years No	No
Braun and Zir (2005) Hawaii	Provision of eight one hour long education sessions. Focus on lived experiences.	n=8 RGNs n=86 HCAs n=6 social workers n=4 activity aids	n=10	I	No	Eight hours No	No
Keay et al (2000/3) USA	Development of a general palliative care curriculum for physicians.	n=2 physicians (pilot) n=12 physicians (after pilot)	n=1 (pilot) n=5 (after pilot)	I+O	Yes	Pilot one day Then half a day Yes-follow up audit after a few months	No
Hanson et al (2005) USA	Established a palliative care leadership team. One day conference followed by six monthly educational sessions and six monthly technical assistance meetings	n=not given but all staff involved	n=9	O+RS	Yes	Two years No	No

Study Country	Description of intervention	Study sample		Individual (I) Organisational (O) or Role Specific intervention (RS)	Reported evidence of change in practice	Study/intervention length Evidence of evaluation occurring after the study period was completed	Evidence of an initiative built into the implementation to enable sustainability after the time limited study finished
		Participants	Number of nursing care homes				
Penrod et al (2007) USA	Trained an interdisciplinary team. Developed and implemented a web based palliative care report card for performance monitoring and improvement.	n=not given but interdisciplinary palliative care team	n=3	I+O+RS	Yes	Five months Yes-ongoing completion of a report card	Yes-completion of a report card for four years
Hill et al (2005) USA	Two days training to a nominated leadership team following a needs assessment of a nursing care home. Developed two action plans.	n=298 RGNs and HCAs	n=109	I+RS	Yes	Three years Yes-six months self reported evaluation	No

The second approach taken, used by seven studies, was learning through the education of link nurses (Table 4.6). Link nurses are individuals who work within a generalist setting but develop specific interest and knowledge in another area in order to 'link' that interest to their own practice area (Partington et al 2008). They are supported by other practitioners and disseminate the information they gain from this support, within their own work setting. The approach taken varied considerably, from agreeing to attend educational sessions to signing an agreement to provide in-service training (and evidence of doing so) and to evaluate the teaching aids they were provided with, within six months (Erske et al 2006). This approach resulted in one study, out of seven, providing evidence of change in practice (Erske et al 2006).

The third approach taken, used by two studies, was learning through reflective practice (Table 4.6). Within one study, this approach was action learning and within the other action research. Learning occurred by the nursing care home participants being supported to work through and resolve specific issues. Such support was provided across nursing care homes from nurse manager to nurse manager (Hewison et al 2011) or within a nursing care home, from colleague to colleague (Hockley et al 2006/2011). Both approaches evidenced change in practice.

The final approach taken, used seven studies, involved multimodal interventions (Table 4.6). These interventions incorporated a variety of mechanisms for learning. A noticeable difference within these studies was that for six of the seven studies, the intervention incorporated changing and/or developing in house policies to guide practice. Five studies provided evidence of change in practice, following the

interventions implementation. Two involved the collection of audit data on performance and three the development of projects/action plans.

Within these 23 studies (Table 4.7) the focus of learning varied. It included:

- Individual learning only (two studies)
- Individual and organisational learning (six studies)
- Individual and role specific learning (five studies)
- Organisational learning (four studies)
- Organisational and role specific learning (three studies)
- Individual, organisational and role specific learning (three studies)

Many more countries had implemented end-of-life care education and/or training interventions in nursing care homes than the LCP/ICP and the GSFCH programme. However, there was great variety in the way these interventions were implemented, with only eight (about a third) evidencing change in practice (Table 4.7).

4.4: Study sites

Nineteen studies report the effect of implementing education and/or training interventions within a total of n=374 nursing care homes. The LCP/ICP was implemented within 19% (n=71) nursing care homes and the GSFCH programme within 31% (n=116).

Most of the education and/or training studies had been undertaken within the USA (n=9). The remainder were undertaken in UK (n=7), Ireland (n=3), Canada (n=1), Hawaii (n=2) and Denmark (n=1). The LCP and the GSFCH programmes were

developed within the UK and all but one study was undertaken within the UK. Within the literature sourced the UK was the only country with evidence of implementing end-of-life care, in nursing care homes, through the use of all three interventions. This may be a consequence of policy recommendation by the Department of Health (2008).

4.5: Study participants

Total participant details are not always reported within the intervention. Participants within the GSFCH programme were care staff but also included external facilitators, bereaved relatives, residents, family members, GPs and nurse managers. As the LCP/ICP and GSFCH programme interventions are systems based changes, it is surprising that there is little evidence of residents' feedback within the studies; across all the studies only 18 residents participated.

Three education and/or training studies only provided details of study participants, not study sites. One of these provided no details of their study sample, in respect to participants or site. Where study participant details were provided, most interventions involved staff undertaking a variety of roles. One study only included ancillary staff (Parkes et al 2005) and another only physicians (Keay et al (2000/3). Froggatt (2000a) reported that as well as the intervention impacting on the individual participant's knowledge and confidence, the nursing care homes cancer residents also directly benefitted from the staff's attendance at the end-of-life care education and/or training intervention. Benefits for residents were also identified by Hanson et al (2005) and Keay et al (2000/03).

4.6: Change agent

Specialist Palliative Care services acted as change agents within 18 out of 23 studies and provided this role for all seven studies implementing the LCP/ICP. The historical background of palliative care means that expertise useful in end-of-life care interventions lie within the field of Specialist Palliative Care (SPC). The change agents involved with studies concerned with the implementation of the GSFCH programme in nursing care homes is less clear. All but one of the workshops in the studies under scrutiny were run by the central GSF team. Only Hockley et al (2012a) was based in a SPC centre. However, three of those implementing the intervention had access to external facilitators, who had a SPC background (Hockley et al 2012a, Hockley et al 2008/10/Watson et al 2010 and Seymour and Froggatt 2009/Seymour et al 2010). This may have been the same for others but the detail was not reported.

One study was instigated from within the nursing care home, by a practitioner whose previous role had been within SPC (Moran 2009). The nursing care home was opening two SPC beds and so the drive for implementation was internal. The clinical nurse manager in the nursing care home recognised a need to develop an end-of-life care philosophy within the home. This was in order for the staff to meet the needs of residents. With the exception of Moran (2009), none of the education and/or training interventions were initiated and implemented solely by nursing care home staff.

Within seven of the education and/or training studies, link nurses from within the nursing care home were appointed, with the intent that they would in time become change agents themselves and continue to sustain the intervention (Table 4.6). Whilst this was the intent, it did not always occur. Waldron et al (2008) reported that that

83% (n= 25) respondents had not commenced cascading training within their nursing care homes at the end of their study, Whilst, the engagement, learning and development of a nominated internal change agents varied with implementation of the LCP/ICP (see 4.3.2) it occurred with all studies implementing the GSFCH programme as two or three staff from each nursing care home were nominated to attend the workshops.

4.7: Factors that enabled the intervention to be implemented into practice

This thesis focuses on the implementation of the GSFCH programme, a programme that consists of three distinct phases. The factors within this review, that enabled the end-of-life care intervention to be implemented into practice, are reported in relation to these phases; the Preliminary Phase; the Implementation Phase; and, the Consolidation Phase.

There were 18 factors that were either demonstrated within the study, or recommended on completion of the study, to take account of when initiating, implementing or sustaining an end-of-life care intervention (Tables 4.8-4.10). The role of the nursing care home manager and environmental constraints were also identified as important factors irrespective of the phase.

Table 4.8: Preliminary Phase – preparation before the intervention’s implementation

Studies	Needs assessment		Funded places (no cost to nursing care home)		Provided locally		Establish a SPC link		Needs an internal champion either: Present (P) or (M) More than one champion		Commitment/ enthusiasm		Nursing care home has good basic care	
	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²
GSFCH*	2		2	1	2	1	5		(P) in four studies (M) in one study)	(M) in one study	4		3	
LCP/ICP*	1		2		1		4	1	(P) in five studies		3	1	1	
Education and/or training	9	1	12**	3	8		10		(P) in six studies and (M) in five studies	1	12			

Key: ¹ - factors demonstrated within the study to be important when preparing to implement an intervention

² - factors recommended on completion of the study to be important when preparing to implement an intervention

■ No evidence

*one study spanned LCP and the GSFCH programme as it incorporated one nursing care home implementing the GSFCH and another the LCP only

** within two additional studies the nursing care homes paid to participate - 14 studies in total considered the factor funding

Table 4.9: Implementation Phase – requirements during the intervention’s implementation

Studies	External facilitator either: Present (P) Past care home experience (PE) Supported (S) Local (L)		Utilisation of staff experience		Supportive GP		Inform Inspectorate and/or Government		Flexibility in course delivery		Meeting staff across nursing care homes		Include all staff groups		Evaluation mechanism /audit data	
	demonstrated ¹	recomm- ended ²	demon- strated ¹	recomm -ended ²	demon- strated ¹	recomm -ended ²	demon- strated ¹	recomm -ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm -ended ²	demon- strated ¹	recomm -ended ²	demon- strated ¹	recomm -ended ²
GSFCH*	(P) in one study (L)+(E) in two studies (S) in one study (L)+(PE) in one study				6		1		1	2	6		4	2		1
LCP/ICP*	(P) in two studies (L)+(E) in one study		2		4		1	1	4		3		3	1	4	
Education and/or training	(P) in three studies (S) in one study (E) in one study	(PE) in one study that also demon- strated this	9	1	2				13		4		12		3	

Key: ¹ - factors demonstrated within the study to be important during the implementation of the intervention
² - factors recommended on completion of the study to be important during the implementation of the intervention

■ No evidence

*one study spanned LCP and the GSFCH programme as it incorporated one case study implementing the GSFCH and another the LCP only

Table 4.10: Consolidation Phase -- requirements following the intervention's implementation

Studies	Completion of the programme				Format for a sustainability initiative							
	Certificate/ accreditation recognition		Time – cultural change takes time		Audit data shared back with the nursing care home staff		Ongoing education		Palliative care part of induction		Skilling up an internal facilitator within the nursing care home	
	demonstrated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²	demon- strated ¹	recomm- ended ²
GSFCH*		3		2				1	2			
LCP/ICP*								2				
Education and/or training	4	1	2		4		3	2			7	

Key: ¹ - factors demonstrated within the study to be important when preparing to implement an intervention
² - factors recommended on completion of the study to be important when preparing to implement an intervention

■ No evidence

*one study spanned LCP and the GSFCH programme as it incorporated one case study implementing the GSFCH and another the LCP only

4.7.1: The Preliminary Phase: prior to the intervention commencing

Within the studies, seven factors were identified to be important prior to implementing an end-of-life care intervention into practice (Table 4.8). These factors included: the intervention being based on an identified need; funding being provided; the intervention being delivered locally; the nursing care home having a link to SPC; having an internal champion/s; being committed, enthusiastic and a nursing care home already providing good basic care.

The importance of not imposing an intervention on a nursing care home but working with staff need was an important element within 12 of the studies (Table 4.8). One additional study recommended it. With respect to funding, ensuring education and/or training interventions were provided without charge, or at a reduced charge, were highlighted by 16 of the studies, whilst two charged for the intervention they were providing. Interestingly, the two studies that charged (Partington et al (2008) and Heals (2008) were both able to sustain their intervention four years after it had started (Table 4.7). With the LCP/ICP funding of staff time to attend may have enabled Mathews and Finch (2006) to include all RGNs and HCAs in the implementation of their intervention. Seymour and Froggatt (2009) noted that in one nursing care home, even when training was free to attend, staff needed to attend in their own time. The GSFCH intervention was initially funded by the NHS end-of-life care programme (Clifford et al 2007). However, this funding only covered the cost of the workshops, with other costs such as attendance at the course, the cost of staff attending and backfill costs needed to be met by the nursing care home. It could be argued from Partington et al (2008) and Heals (2008) that paying for education/training made organisations more committed.

Eleven of the education and/or training intervention studies stated that the intervention should be provided locally, with a further four recommending this. Up until 2009 the GSFCH intervention was only available in one location (Birmingham, England), and so did not offer an option for local provision. Clifford et al (2007) reported that it was not always possible for nursing care home staff to obtain funding to attend distant workshops in Birmingham. This lack of funding was amongst the reasons that 16 homes withdrew from the programme.

Nineteen studies ensured a link with SPC occurred, with one additional study recommending this. The importance of this was particularly highlighted when initiating the LCP/ICP and/or GSFCH programme (Table 4.8). Seymour and Froggatt (2009) reported an essential component of a palliative care LCP/ICP intervention was the need to ensure the senior nursing care home staff had end-of-life care expertise. Prior to the LCP and GSFCH intervention commencing, the senior staff all gained certificates in palliative care which enabled them to show leadership to junior staff and affected their approach to, and education of, other staff within the nursing care home. Hockley et al (2004) reported a similar finding to that regarding the implementation of the ICP, in that they found a significant number of key champions had already undergone a validated 'Palliative Care for the Elderly' course. Perhaps with this experience in mind, in a later study implementing the GSFCH programme (Hockley et al 2008) additional training was provided by with 73% of GSFCH coordinators attending a four-day Macmillan 'Foundations in Palliative Care for Care Homes' training course, before the first GSFCH workshop.

Enthusiasm, commitment and the presence of a champion within the nursing care home aided the implementation of all three interventions. With respect to having a champion, seven of the 23 studies that demonstrated or recommended the need for an internal champion, for the intervention, also advocated they had more than one. Such a recommendation was important due to staff turnover. However, Thomas et al (2005) believed more than one person was required to facilitate the GSFCH intervention. It also ensured that the intervention continued to be implemented when one individual was absent.

A final factor, only mentioned in relation to the GSFCH programme and the LCP/ICP, was the importance of pre-existing good basic care. Thomas et al (2005) and Clifford et al (2007) both stated that prior to the intervention occurring, the participating care homes reported that they already had high standards of care. Thomas et al (2005) believed care homes needed core competencies in place, before starting the programme with only those care homes with a star status 2 (score ranged 0-3 where a score of 3 was the highest) given by the regulators being allowed to take part. If such competencies were absent there was a strong chance of the intervention failing, thereby devaluing the initiative. They believed consideration should be given to the assessment of basic nursing care before the GSFCH intervention was introduced. As a result they went on to suggest that an important component of the GSFCH intervention was the use of a self assessment learning tool. Clifford et al (2007) also identified pre-existing routine use of an out-of-hours form, by the care home staff, also impacted on the interventions successful implementation.

4.7.2: The Implementation Phase: during the implementation

Implementing an intervention took time. All but one of the 36 interventions were implemented over time and not as a single isolated event. Dowding and Homer (2000) were the only study to hold a one day training event, described as a 'pilot' study day, for HCAs with no follow up opportunity provided.

Eight factors were identified within the studies that supported implementation of the intervention into practice. These included: having an external facilitator; utilisation of staff experience, a supportive GP, informing their Inspectorate and/or Government, flexibility in course delivery, meeting staff across other nursing care homes, including all staff groups and, using an evaluation and/or audit mechanism (Table 4.9).

External facilitators were instrumental to the initial implementation of the LCP/ICP and the GSFCH intervention, within eight of the included studies. Specific recommendations were made within the studies: that the external facilitator was local (three studies); had previous care home experience (one study); were supported (one study); and, were experienced in the role (three studies). Regarding external professionals, Clifford et al (2007) and Thomas et al (2005), both referred to the essential need for an external facilitator when implementing the GSFCH intervention.

It would appear however that provision should be shaped according to need. Clifford et al (2007) made the specific comment that education sessions provided locally by their external facilitator and held weekly, were too demanding of staff time. Similarly Hockley et al (2008) found only small nursing care homes could manage a weekly review of residents, medium and large homes needed to split the review over two

weeks. This suggests that facilitation and implementation of the GSFCH intervention may need to be flexible, according to staff need and/or availability. Thomas et al (2005) also stated that it was easier when a care home, was supported by an external facilitator who knew the GSF programme well. Five of the education and/or training interventions also demonstrated or recommended the need for an external facilitator. None of the studies identified the specific role or competencies needed to undertake such a role.

During the Implementation Phase of the end-of-life care education and/or training intervention the intervention enabling the nursing care home staff to both articulate their expertise in end-of-life care for older people and to incorporate this into educational programmes was seen as important (Table 4.9). The utilisation of staff experience occurred in nine of the 23 education and/or training interventions (Table 4.9), with reflection and story work forming part of the implementation of all of the GSFCH programme studies and three LCP/ICP studies (Table 4.2 and 4.4). This suggests that implementation of an end-of-life care intervention in practice is aided by working with the expertise and knowledge of staff in nursing care homes.

The value in nursing care home staff working with external professionals was identified. Some of this partnership working was essential for implementation to occur. For example, the support of the GP was highlighted when implementing the LCP/ICP and GSFCH programme but only mentioned within two education and/or training interventions. Three studies implementing the LCP/ICP and GSFCH programme also informed or recommended informing their Inspectorate and/or Government.

Additional factors across all interventions were that the implementation of the intervention should be flexible, include meeting staff from other nursing care homes undergoing the same process and that all staff were included. When evaluating the LCP, Seymour and Froggatt (2009) reported that network LCP meetings were set up by the community matron and the end-of-life care facilitator with 12 nursing care homes. The intention was the nursing care homes would eventually support each other in these meetings, which would be held in turns in each nursing care home. There were no volunteers to lead these LCP meetings so they were disbanded, due to poor attendance and support.

More than 50% of studies implementing the LCP/ICP intervention, highlighted how it could act as an audit tool for quality and evaluation monitoring. This was used within three of the education and/or training interventions and recommended by one of those implementing the GSFCH programme.

4.7.3: The Consolidation Phase: following the implementation

Six factors were identified to be important following the Implementation Phase of the intervention. These related either to the completion of the intervention or to sustaining the intervention in practice (Table 4.10).

One factor relating to the completion of the intervention was the recognition of its completion through certificate and/or accreditation. The GSFCH programme has now introduced an accreditation system. Eight studies made reference to this. Four studies recognised that completion of an intervention takes time because cultural change takes time. The remaining factors related to sustaining the intervention in practice.

Fifteen studies provided evidence of evaluation of the intervention after the study period had been completed (Tables 4.3, 4.5 and 4.7). This demonstrated sustainability of the intervention in practice, at that moment in time (where details were provided this ranged from one month to a year after the study was completed). Only six of these 15 studies described a sustainability mechanism that had been put in place to *maintain* the initiative in practice after the study period had finished. These mechanisms varied (Tables 4.3, 4.5 and 4.7). Although these six studies provided evidence of a sustainability initiative the effect of the sustainability initiative was only measurable in one study. Penrod et al (2007) stated that a web-based report card ensured activity was monitored, with quarterly feedback. Data collection was ongoing with quarterly feedback already provided for four years.

Importantly, the recommendations for sustainability of an intervention in practice correspond to issues raised earlier. Sustainability initiatives varied but included: sharing audit data back with the nursing care home; ongoing education; palliative care becoming part of the induction programme; and, skilling up an internal palliative care/end-of-life care facilitator within the nursing care home. Change in organisations is ongoing. This means to sustain an intervention in practice provision of ongoing education, palliative care forming part of induction and skilling up an internal facilitator are necessary. Organisational change was supported by measurable outcomes (see 3.4.3). This may explain why sharing audit data back with the nursing care home was identified to be important as was leadership. The role of the nurse manager is now considered.

4.7.4: Role of the nursing care home manager

The importance of management being supportive of and/or engaged with the intervention was highlighted within 23 of the 36 studies. The manager enabled education to occur in the nursing care home by coordinating duty rotas, which allowed attendance of staff on a set day, freeing link nurses from the clinical setting and enabling the implementation of change within the nursing care home.

Within a nursing care home setting, ten studies highlighted the importance of support for the nursing care home manager. Seymour and Froggatt (2009) reported that the owners of one nursing care home were very supportive to the manager and agreed with the nursing care home's end-of-life care focus. This in turn meant that they employed above the required ratio of HCAs to residents. As a consequence of this, there was less staff turnover and so noticeable improvement of standards. Ongoing support from the owner now meant that one nursing care home in their study could support other local care homes implementing these interventions. When implementing their education and/or training intervention Curry et al (2009) noted that managers themselves needed peer support and two clinical supervision groups were commenced in response to this finding. Hewison et al (2011) also focused their intervention on the nursing care home managers. Interventions were highlighted to be valuable to management and therefore more likely to be supported by management if:

- the effect of the intervention could continue after the implementation (Parkes et al 2004) and Hewison et al (2011)
- there was audit data collected for evaluation of the intervention (Clifford et al 2007, Jones and Johnstone 2004, Duffy and Woodland 2006, Parkes et al 2004, Kortés-Miller et al 2007, Hanson et al 2005 and Hill et al 2005).

When implementing all three interventions, challenges were noted to arise because nursing care homes are businesses in addition to being an individual's home. As a result, managerially organisational needs and mandatory training could take priority over individual needs (Hockley et al 2008/10, Froggatt 2000, Dowding and Homor 2000 and Waldron et al 2008).

4.7.5: Environmental constraints to consider when implementing an end-of-life care intervention

Four environmental constraints were identified when implementing an end-of-life care intervention. These were:

1. Issues relating to the building such as location (rural), size and if there was building work occurring (Clifford et al 2007 and Hockley et al 2008)
2. Staffing challenges:
 - a. multi-cultural issues (Mathews and Finch 2006, Waldron et al 2008 and Hall et al 2011b)
 - b. rapid turnover (Thomas et al 2005, Hockley et al 2008, Jones and Johnstone 2004, Froggatt 2000a, Partington et al 2008, Curry et al 2009, Waldron et al 2008, McClelland et al 2008 and Parks et al 2004).
 - c. the ratio of staff to residents (Clifford et al 2007)
3. Resources (Hockley et al 2008, Partington et al 2008, Clifford et al 2007, Jones and Johnstone 2004, Moran 2009, McClelland et al 2008 and Hall et al 2011b)
4. Variability in GP cover (Seymour and Froggatt 2009, Clifford et al 2007 and Thomas et al 2005)

4.8: Discussion

These reviews reveal that The Department of Health (2008) have based their recommendation to achieve quality end-of-life care in UK nursing care homes, on limited evidence (Kinley et al 2013a). The evidence base for the LCP/ICP and GSFCH programme currently relate to the UK experience. Whilst both programmes have been implemented beyond the UK (The Marie Curie Palliative Care Institute and the Gold Standards Framework Central Team) only one study occurred outside of the UK.

With respect to end-of-life care, no study reporting on the implementation of an education and/or training intervention met the inclusion criteria for the first review. Widening the inclusion criteria, identified 23 studies reporting on the implementation of, rather than the outcomes from, an end-of-life care education and/or training intervention many of which were undertaken outside the UK. It was while undertaking the second review that evidence of change in practice was identified when education occurred alongside a practice based intervention such as a link nurse programme, reflective learning groups or multimodal interventions. When knowledge about end-of-life care was gained through education and/or training in this manner, it impacted on care provision.

This second review revealed that the LCP/ICP and GSFCH interventions incorporated education including different formats of learning. All the GSFCH and all the LCP/ICP studies provided evidence of change in practice other than three studies (Hall et al 2011b, Seymour and Froggatt 2009 and Seymour et al 2010) (Tables 4.3 and 4.5). This supports the findings from the educational and/or training interventions that

change in practice requires more than education. In effect, the GSFCH intervention included all three interventions as education and/or training initiatives and implementing the LCP/minimum protocol for the last days of life are encouraged as part of its implementation. It is a complex intervention. Understanding more about the implementation of the GSFCH programme may help with the understanding of how new knowledge is learnt and translated into culture and practice.

The format and delivery of the interventions varied. The LCP/ICP and GSFCH programme were interventions that promoted learning at organisational and role specific level. In contrast, learning at an organisational and role specific level was only present in six of the 23 education and/or training interventions (Froggatt et al 2000a/b, Kelly et al 2008/11, Penrod et al 2007, Cheetham 2008, Waldron et al 2008/Hassan et al 2008 and Hanson et al 2005). This suggests that the delivery format of an intervention might also affect its implementation into practice. Further research exploring this concept would need to be undertaken due to the level of evidence of the included studies (see 4.2.5).

Undertaking the second review gave limited understanding of how to sustain end-of-life care interventions in practice. When evaluating the implementation of the GSFCH programme and the LCP, Seymour et al (2009) described a sustainability initiative. Four other education and/or training interventions that incorporated a link nurse programme also provided evidence of a sustainability initiative (Partington et al 2008, Penrod et al 2007, Cheetham 2008 and Heals 2008). The only study demonstrating sustainability and evidence of change in practice was Penrod et al (2007). The GSFCH programme and the link nurse education and/or training intervention skilled up

nominated individuals (GSFCH coordinators or link nurses) within the nursing care home. This enabled sustainability of the initiative as on completion of the intervention they then acted as internal facilitators of the intervention. What remains unknown is how effective this approach to internal facilitation was, due to the absence of longitudinal data.

Collectively, these reviews give a unique understanding, of both the outcome of the Department of Health (2008) drive to promote quality end-of-life care and the process by which this was achieved, in nursing care homes. With respect to how it was achieved, a number of factors, both internal and external to the nursing care home, enabled this process. To understand the specific role of facilitation when implementing the GSFCH programme for this study taking account the influence of other factors would be important. Within the studies identified detail of what was actually provided by the external facilitators, in terms of their activities or their time was missing. The length of the GSFCH programme, alongside the complexity of the intervention and the care home context, makes obtaining this information challenging.

4.9: Limitations

Whilst the evidence on implementation of an end-of-life care education and/or training intervention came from international evidence this was not the case for the LCP/ICP and GSFCH programme. No papers were identified reporting on the implementation of the GSFCH outside of the UK and only one on the use of the LCP/ICP. This was not surprising as both of these initiatives were developed within the UK. Whilst these reviews are based on the process of change, in nursing care

homes, account was taken of the process of change within care homes without nursing and findings were similar.

4.10: Conclusion

Currently the transfer of end-of-life care from theory to practice is occurring through link nurse schemes, the LCP/ICP and the GSFCH interventions. The limited evidence from these reviews suggests that education for generalist settings needs to be set alongside a practice based intervention. However, across all these interventions sustainability after the study is completed is rarely considered and longitudinal data rarely collected.

In conclusion, further research on the process involved when transferring an end-of-life care intervention into practice within a nursing care home needs to be undertaken. Although it is important for this to identify specific outcomes such outcomes will not be achieved unless the level of assistance nursing care homes need for them to be able to achieve and sustain the intervention in practice is also determined. With respect to the GSFCH programme access to an external facilitator was identified to be important during the Implementation Phase of the GSFCH programme. The importance of such facilitation being supported, local, experienced in the role and having experience of working in a care home setting were also identified from the review. However, the detail of such facilitation; the level of assistance; the format of assistance; or, the amount of assistance required or requested from them, for the programmes successful implementation was not identified or addressed. Within the review the role of an external facilitator in the Preliminary Phase and the Consolidation Phase of a programmes implementation was not reported. This study would identify if such a role existed, or was identified as needed, during these phases of the GSFCH programme.

The next chapter details the methodology used within this research study to achieve this understanding. It takes account of what these reviews have identified as important when implementing an end-of-life care intervention within the context of nursing care homes and what is already known about facilitation, in relation to organisational change.

Chapter Five - Methodology

The study's research questions, aim and objectives are identified at the start of this chapter. Following this the decision to use mixed methods as the research design will be explained. The use of an adapted version of Morse's (2010) mixed methods, as the research design, raised questions concerning epistemology and data analysis which are addressed. Whilst such questions were not unique to this study, they were more complex as both quantitative and qualitative data was collected. Information is therefore given not only about the methods for data collection and data analysis, but also about how, why and when these data sets were integrated. Issues of quality and rigour were addressed within each data set and also across the combined data sets. Finally ethical issues were considered.

5.1: Research questions, aim and objectives

The study aimed to answer two research questions:

1. What is the effect of different approaches to facilitation on end-of-life care practice within UK nursing care homes, when implementing the Gold Standards Framework in Care Homes (GSFCH) programme?
2. How are these different approaches perceived by those providing and those receiving such facilitation?

The primary aim of the study was to identify:

The role of facilitation when implementing an end-of-life care initiative (GSFCH) within nursing care home practice.

In order to achieve the aim five objectives were identified:

1. To understand current knowledge about implementation of new end-of-life care initiatives within nursing care home practice.
2. To evaluate three approaches to facilitation that supports the implementation of the GSFCH programme.
3. To describe the experience of those providing and those receiving these approaches to facilitation.
4. To identify the barriers and enablers to the implementation the GSFCH programme.
5. To make recommendations for a future model of facilitation.

5.2: Research design

The choice of mixed methods as the research design for this study occurred after exploring and considering the concept of theoretical perspectives or paradigms which is now discussed.

5.2.1: Theoretical perspectives

Theoretical perspectives or paradigms refer to the way of looking at the world. They are an approach to understanding and explaining the human world and society (Crotty 2009).

Whilst Crotty (2009) recognised and described two paradigms, those of positivism and interpretivism, Johnson et al (2007) describes a third - the use of mixed methods. They suggest that mixed methods respects the wisdom of the other two paradigms and in doing so attempts to include multiple views, positions, perspectives and standpoints

(which always include qualitative and quantitative research). However, others disagree. Both Kuhn (1996) and Sale et al (2002) believe that because of paradigmatic assumptions, even when quantitative and qualitative research label phenomenon identically, these labels refer to different things.

5.2.1.1: Mixed methods

The recognition of mixed methods as a third paradigm by Johnson et al (2007) occurred following their review of the literature. The older literature first refers to the use of mixed methods as 'triangulation' (Brennan 1992). Whilst triangulation was originally a term associated with surveying and navigation, Campbell and Fiske (1959) used this term when they discussed the value of using at least two methods, in one study of the same object. This term was then developed by Denzin (1970) who acknowledged that triangulation may refer to variety of methods, but also believed, it could refer to variety occurring in one study in relation to data, investigators and methodologies. Regardless of the approach taken the benefit of triangulation is that it represents a solution that overcomes the 'intrinsic bias' (Denzin 1970) that comes from studies using one method, one observer or one theory. The main purpose of using triangulation in a study was still to confirm the accuracy of one's data. This same term was used by Fielding and Fielding (1986), but they also introduced a second concept to triangulation, that of completeness i.e. its ability to generate a more complete picture of the phenomena under investigation. Jick stated that rather than triangulation just confirming the validity of findings it captured 'a more complete, holistic, and contextual portrayal of the unit(s) under study' (1979: 603). King (2004) referred to this as the generation of a richer picture.

The use of more than one method in a single study has continued to develop. Rather than triangulation, this is now referred to as mixed methods. Within such studies, there is a recognised role for each individual method that adds independent value or depth to the study. Each method contributes to answering a research question, rather than simply acting, as it did originally, as a means to overcome the known weaknesses within another method. The ‘different methods...are therefore necessarily interdependent while retaining their paradigmatic modalities’ (Moran-Ellis et al 2006: 52). Johnson et al conclude that ‘mixed methods research is an intellectual and practical synthesis based on qualitative and quantitative research’ (2007:129). They labelled it the third methodological or research paradigm.

5.2.2: Epistemology

Whilst mixed methods is recognised as a research paradigm, its use in practice is noted to present specific challenges. The main challenge is epistemological (Sale et al 2002). Addressing and resolving this was essential when the decision was made to use mixed methods as the research design in this study.

Epistemology recognises three types of knowledge. Knowledge is either: intrinsically present and exists independently of consciousness (objectivity); is constructed by active engagement with the world and cannot just be discovered (constructionism); or, meaning is imposed on the object by the subject (subjectivism). Epistemology impacts on the theoretical perspective or paradigm.

Moebius recognises that questioning the two traditional paradigm boundaries (positivism and interpretivism) results in the arrival of an ‘epistemological crisis’

(2002: 1). However, Moran-Ellis et al (2006) offers a possible solution. They state that it is the outcome of the integration of data in mixed methods studies, rather than the process of integration, that can be positioned epistemologically.

5.2.2.1: This study in relation to epistemology

Researching real life situations is complex. As reality is complex I recognised that undertaking this research study, in nursing care homes, was likely to be complex. Foss and Ellefsen (2002) believe different types of knowledge were needed in order to understand all aspects of reality. They recognised that the use of different methods enabled different types of knowledge to be gained. The view of knowledge and reality held by Foss and Ellefsen (2002) is supported within this study. With this recognition came acknowledgment of the need for an alternative epistemological position.

The use of a mixed methods study design for this study enabled knowledge about reality to develop through triangulation. It follows the view of triangulation postulated by Moran-Ellis et al (2006:47) that ‘triangulation is an epistemological claim concerning what more can be known about a phenomenon when the findings from data generated by two or more methods are brought together.’

Foss and Ellefsen (2002), King (2004), Sale et al (2002) and I conclude that epistemological triangulation offers a solution. It meant that data generated within this study could be understood in relation to the purpose for which it was created (Brannan1992).

5.2.3: Mixed methods as the research design

The decision to undertake a mixed methods research design was as a consequence of three factors: the complex nature of the research focus, ensuring fidelity and enabling complementarity.

Firstly, this study's aim was to evaluate the role of providing facilitation to implement a complex end-of-life care intervention. Understanding the outcome as well as the process of how to facilitate the GSFCH programme was important. Not only was the intervention complex, but the facilitation taking place was in complex environments. When evaluating complex interventions in palliative care Farquhar et al (2011) report on the value of a mixed methods approach. A recent publication supported this approach in end-of-life care, as well as palliative care, research (Farquhar et al 2013).

Secondly, the collection and use of the quantitative data on how facilitation was delivered would ensure fidelity when implementing the GSFCH programme. As facilitation was delivered over a two year period, the only way to evidence exactly what facilitation a nursing care home received, was to keep a record of this over time.

Finally, it was believed the use of two methods would provide a more complete picture (complementarity) about the concept of facilitation whereby the objective view of the world (from the quantitative data) would be complemented by the subjective view of the world (qualitative data). Denzin recognised this when he stated 'sociological reality is such that no single method, theory or observer can ever capture all that is important' (1970: xii).

5.2.3.1: Typologies within mixed methods research design

Two decisions influence the choice of a mixed methods design. The first decision is identification of the core method (Morse 2010) and the less-dominant method (Padgett 2012) of the study. The core method is that which answers the majority of the research question. This is indicated by uppercase letters as either qualitative (QUAL) or quantitative (QUANT). The remainder of the research questions are then answered by another method, which is indicated by lowercase letters and also may be either qualitative (qual) or quantitative (quan). This is referred to as the supplementary (Morse 2010) or the less-dominant method (Padgett 2012). The second decision in a mixed methods design relates to the timing of data collection. Data may either be collected simultaneously (at the same time and indicated by a +) or sequentially (immediately following the core component and indicated by a →).

The research design for this study is illustrated in Figure 5.1. This diagrammatic representation identifies the different components and stages of the research study as well as their separation and integration:

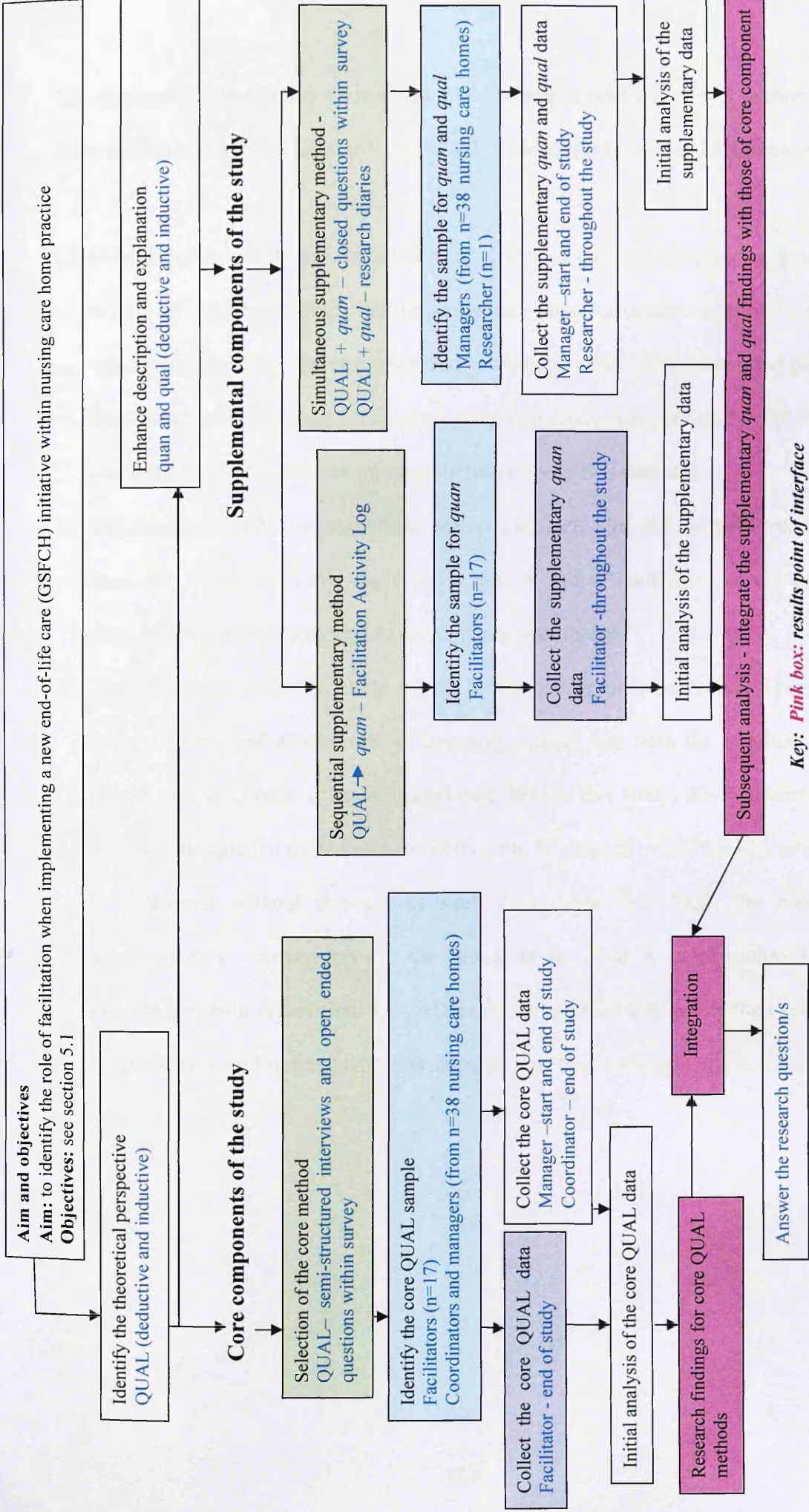
1. Core component/s
2. Supplementary component/s

Morse (2010) states that the core component of a project forms the theoretical drive and also the theoretical base for presentation of study results. The main focus of the design of this study was exploratory and the choice of core QUAL research methods therefore reflects this. The core method (Figure 5.1) aimed to generate knowledge that was constructed both by those receiving and by those providing facilitation. The Soft

Systems Framework mnemonic *CATWOE*⁶ (Checkland 1999) introduced in Chapter three formed the template for data collected within the interviews and framed the analysis and interpretation of all the core data that was collected.

In addition to the core component of the project Morse (2010) identified a supplementary component/s. What is of crucial importance to any research design, is its outcome i.e. its ability to answer the research question/s. In order to be able to evaluate three different approaches to facilitation of the GSFCH programme, a supplemental *quant* data (Facilitation Activity Log) was incorporated. This would, unlike the core *QUAL* data, be able to provide detailed information about the facilitation that was actually provided by the facilitators, during the two year study. An accurate record of exactly what facilitation was provided was important, although not essential, in order for the research questions to be answered. Additional sources of supplemental *quan* data included information from the closed questions within the nursing care home manager's questionnaires and *qual* data from the researcher's diaries that were kept. This data provided information on the nursing care home context and the demographic details of the participants and acknowledged my presence within the study settings.

⁶ *CATWOE* refers to the organisation undergoing the change (Customer), the person implementing the change (Actor), the process of change (Transformation), any external worldwide influences (Worldview), management factors (Owner) and any environmental factors (Environmental constraints).



Key: **Pink box:** results point of interface

Purple box: interface to ensure accuracy of the collected supplementary data

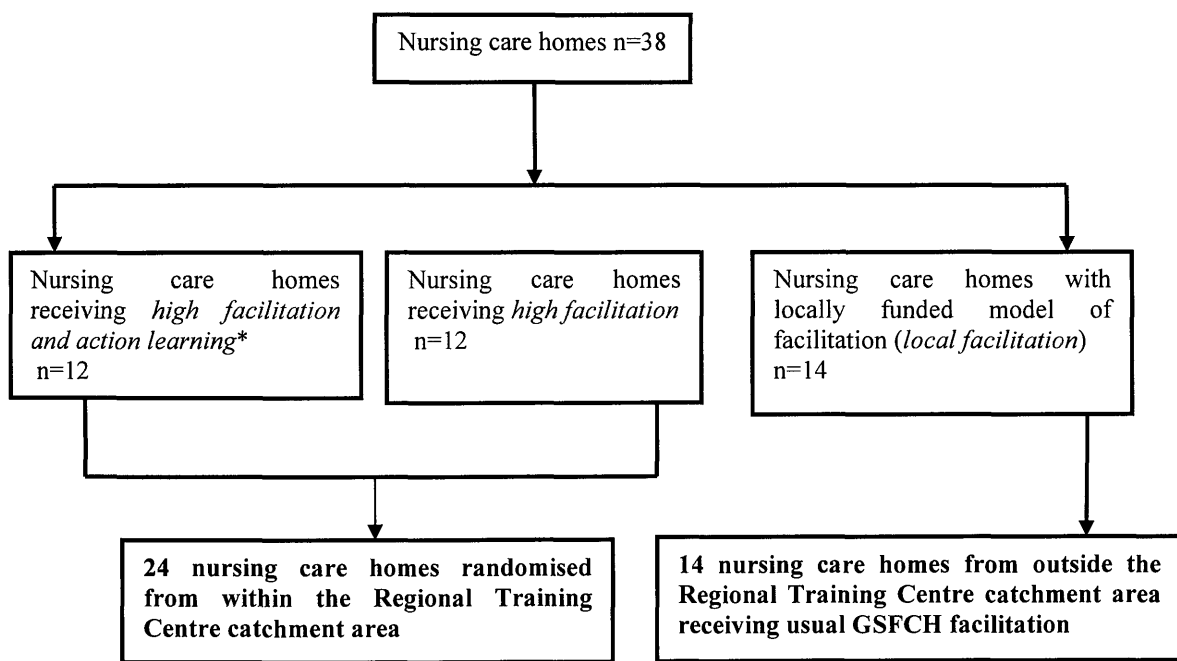
Figure 5.1: An overview of the research design

The core and supplementary component of this research design, differed in three ways from the mixed method design that Morse (2010) identified. Morse (2010) suggested:

1. Core component data are collected prior to that of the supplementary component. Within this research design, the supplementary *quan* Facilitation Activity Log data was recorded during the two year study, whilst the core semi-structured external facilitator interviews were undertaken at the end of the two year study. The purple box in Figure 5.1 shows the interface between these two data sets.
2. Supplementary data are incomplete within a project. This did not hold true, as the *quan* data collected in this study was a total record of facilitation of the GSFCH programme that was provided to each nursing care home.
3. Theoretical drive for the study would be qualitative or quantitative. The mixed method theoretical framework of this study meant that both the qualitative and quantitative data were of equal importance. Within this study, the qualitative data was only designated to be the core component, because the research aim could not be answered without the use of such data. Data from both the core and supplementary components of the study both made a contribution to the knowledge about facilitation. This relates to complementarity where the usefulness of qualitative and quantitative data depends on their appropriateness for a given task.

5.3: Sampling Strategy

This study was undertaken in 38 nursing care homes, in south-east England. These same 38 nursing care homes were also taking part in a Cluster Randomised Controlled Trial as described in Chapter one. Twenty-four nursing care homes received *high facilitation* or *high facilitation and action learning*. Fourteen nursing care homes received usual GSFCH facilitation (*local facilitation* funded within their locality) to help them implement the GSFCH programme within their nursing care home. (Figure 5.2)



* action learning = nine months of action learning with the nursing care home manager

Figure 5.2: The nursing care home sample

5.4: Participants

The participants were recruited from two sources.

1. Staff who were employed by and working within, the nursing care home:
 - Nursing care home manager
 - GSFCH coordinator/s
2. Staff who were external to the core nursing care home staff and not specifically employed by them to provide this role:
 - External facilitator/s

5.4.1: Nursing care home manager/s

Each participating nursing care home had a home manager. The nursing care home managers at the start and completion of the study would not necessarily be the same individuals as over a two year study period, nursing care homes may shut and staff changes occur.

5.4.2: GSFCH coordinator/s

The GSFCH coordinator was a member of the participating nursing care home staff, who was nominated to oversee and encourage the implementation of the GSFCH programme, within a specific nursing care home. The number of GSFCH coordinators varied from one nursing care home to another (Table 1.1). The GSFCH coordinators from whom data would be collected were those working in this capacity, within the 38 nursing care homes, a year after the final GSFCH workshop.

5.4.3: External facilitator/s

External facilitator/s were those individuals who provided facilitation of the GSFCH programme to the participating nursing care homes over the two year study period.

The inclusion and exclusion criteria for each of the participants is given in Table 5.1

Table 5.1: Inclusion and exclusion criteria for study participants

Participants	Inclusion Criteria	Exclusion Criteria
Nursing care home managers	<ul style="list-style-type: none">- The managers who provided consent for their nursing care homes to take part in the CRCT.- The managers of the nursing care homes taking part in the CRCT, in post a year after the final GSFCH workshop.	<ul style="list-style-type: none">- Nursing care home managers associated with nursing care homes that did not meet the CRCT inclusion criteria.
GSFCH coordinators	<ul style="list-style-type: none">- The GSFCH coordinator/s of the nursing care homes taking part in the CRCT, in post a year after the final GSFCH workshop.	<ul style="list-style-type: none">- GSFCH coordinators associated with nursing care homes that did not meet the CRCT inclusion criteria.- GSFCH coordinators that were not part of the implementation of the <i>Phase 6</i> GSFCH programme.
External facilitators	<ul style="list-style-type: none">- All professionals who had provided GSFCH facilitation to the participating nursing care homes, for any period of the two year study.	<ul style="list-style-type: none">- External facilitators associated with nursing care homes that did not meet the CRCT inclusion criteria.

5.4.4: Process of recruitment of the nursing care home managers

Recruitment to this study occurred at the same time as recruitment of the nursing care homes to the CRCT. Every nursing care home manager who had paid for their home to participate in the 2009 GSFCH programme (known as *Phase 6*) at the Regional Training Centre was contacted by phone and invited to attend a presentation about the study. Managers from the nursing care homes geographically local to the Regional Training Centre attended the GSFCH programme on different days to managers from nursing care homes outside the area.

After presentation of the study the nursing care home managers attending each presentation had the opportunity to ask questions. For all the nursing care homes that met the inclusion criteria, consent to participate in the study was obtained. The consent form was also signed by the deputy manager and the owner or the regional manager of the nursing care home. It was hoped this process of consent would provide the nursing care home manager with support, as other senior members of staff knew about, and supported the study.

If the nursing care home manager changed, the new manager was contacted by telephone. An information sheet and a copy of the original consent form was sent to them to sign and post back. A phone call was planned following their receipt of this, to discuss and answer any queries and to make an appointment to meet the nursing care home manager, at the next visit to their nursing care home.

5.4.5: Process of recruitment of the GSFCH Coordinator/s

Recruitment of the GSFCH coordinators was through the nursing care home manager. As part of the CRCT consent process, managers provided consent for all the staff employed by the nursing care home to be approached and their participation requested. This included permission to approach the GSFCH coordinators that they had appointed.

5.4.6: Process of recruitment of the external Facilitator/s

Recruitment of the external facilitators was more complex. At the start of the GSFCH programme, the details of all the external facilitators were unknown. The nursing care homes did not need to complete any details regarding a external facilitator, on their

GSFCH application form. It was only at the first GSFCH workshop that details of facilitators could be obtained. For those external facilitators employed outside the National Health Service, permission to approach them for their individual consent to participate in the study, was sought from their employers. A number of the nursing care home external facilitators were identified as being National Health Service employees. As a result, permission to approach them for individual consent occurred via their local National Health Service Research and Development department. Once permission was granted, individual consent to participate in this study could then be obtained from each external facilitator. The same recruitment process, as described above, was followed for all external facilitators coming into post, as the study progressed.

5.5: Methods of data collection

Four methods of data collection were used:

1. Interviews
2. Surveys
3. Facilitation Activity Log
4. Researcher's diary

The timing of each of these methods of data collected is given in Table 5.2. The four methods for data collection are now considered and the rationale for their use.

Table 5.2: Data collection methods and associated participants

Time of data collection	Method of data collection and associated participant				
	GSFCH coordinator questionnaires	Nursing care home manager questionnaires	External facilitator interviews	Facilitation Activity Log	Researcher's diary
Start of study (2009)		X		X	X
Throughout study (2010)					
End of study (2011)	X	X	X		

Key: X=data collection period

5.5.1: Interviews

Interviews are the predominant method of qualitative data collection (May 1991 and Burnard 2005). They enable the collection of a verbal interpretation from a participant, about a particular issue. The emphasis of this method of data collection is that it is an account of participants' ways of classifying the world, their beliefs and their behaviour in that world (Green and Thorogood 2005). It is not an objective record of what actually occurred since each story will be uniquely individual, contextual and represents a person's interpretation of events.

5.5.1.1: The rationale for using interviews within this study

The experience of the external facilitators was central to understanding the process and effect of providing different formats of facilitation to support the implementation of the GSFCH programme. It was hoped that the interview would give those involved an opportunity to discuss their views of facilitation and to explore in detail the facilitation they had provided. During the interview, details about the type of facilitation they had provided could be confirmed before exploring their opinion of

how this had actually worked out in practice. Interviewing would hopefully enable interaction around and between the different sets of data.

5.5.1.2: The format of the interview

Semi-structured interviews were undertaken (Appendix Four). These are the most commonly used type of interview (Polit and Hungler 1995, Green and Thorogood 2005). The interviewer has a topic guide to follow, but within this, flexibility exists to explore subjects that may arise and to probe for further information as the opportunity occurs. However, unlike a structured interview format, it is not possible to be certain that the way questions are asked or the phrasing of a question is responsible for any differences in the answers. Barnball and While (1994) raise an interesting debate about the concept of validity in such a situation suggesting perhaps it is about ensuring that the correct meaning of the question is conveyed to the participant rather than the use of identical words. Rather than posing a potential problem, it could be argued that phrasing a question differently is in fact a strength of the semi-structured interview.

Within this study the semi-structured interview schedule provided a guide. It ensured that all six components of the Soft Systems Methodology (CATWOE) were addressed with each participant interview (see 3.2.2). Table 5.3 indicates the relationship of the interview questions to the six components of Soft Systems Methodology.

Table 5.3: CATWOE mapping to the interview questions

CATWOE Mapping	
CATWOE	Interview Question
Customer	<ul style="list-style-type: none"> • Talk a little about the nursing care home – context <ul style="list-style-type: none"> ○ Internal enablers/barriers ○ External enablers/barriers • Was anyone other than them providing a role in the nursing care home that would have contributed to the GSFCH facilitation • Explore what level of facilitation were they able to offer to nursing care home (frequency of visits/contacts etc) and how this worked. • Explore what was difficult about their role • Anything else they would like to say
Actor	<ul style="list-style-type: none"> • Length of time they have been qualified as a nurse • Where they undertook their nurse training • Background in end-of-life care/palliative care/qualifications • Grade/band of external facilitators post • Full time/part time (hrs per week) • Any other associated employment • Previous experience of facilitation of the GSF or GSFCH • Any roles in the past that they feel have enabled them to undertake the role of a GSFCH external facilitator • Number of nursing care homes they facilitated • What does the term facilitation mean to them • Looking back would they have done anything differently <ul style="list-style-type: none"> ○ What facilitation, if any, are they able to offer to the <i>Phase 6</i> nursing care home (frequency of visits/contacts etc) now. • Explore what support they received whilst undertaking this role and their opinion • Was anyone other than them providing a role in the nursing care home that would have contributed to the GSFCH facilitation • Explore what level of facilitation were they able to offer to nursing care home (frequency of visits/contacts etc) and how this worked. • Anything else they would like to say
Transformation	<ul style="list-style-type: none"> • Talk a little about the nursing care home – context <ul style="list-style-type: none"> ○ Internal enablers/barriers ○ External enablers/barriers • Explore what they found positive about their role as an external facilitator • Explore what was difficult about their role • Looking back would they have done anything differently <ul style="list-style-type: none"> ○ Explore their overall opinion of their role as an external facilitator and what they think may aid this role in future • Was anyone other than them providing a role in the nursing care home that would have contributed to the GSFCH facilitation • Explore what level of facilitation were they able to offer to nursing care home (frequency of visits/contacts etc) and how this worked.
Worldview	<ul style="list-style-type: none"> • Anything else they would like to say
Owner	<ul style="list-style-type: none"> • Talk a little about the nursing care home – context <ul style="list-style-type: none"> ○ Organisational enablers/barriers • Anything else they would like to say
Environmental constraints	<ul style="list-style-type: none"> • Talk a little about the nursing care home – context <ul style="list-style-type: none"> ○ Environmental/financial enablers/barriers • Anything else they would like to say
Other	<ul style="list-style-type: none"> • Anything else they would like to say • Ask if they can give a summary as to how facilitation of the GSFCH programme should be provided

External worldview influences may have been experienced, and therefore potentially reported, in relation to any CATWOE element. Consequently, in this interview schedule, whilst information on this element was captured and reported, it was not specifically asked about. A benefit of a semi-structured interview was that it opened up the possibility to hear about other elements that the facilitator identified to be important when implementing the GSFCH programme. The addition of ‘other’ within the table was in recognition of this possibility.

5.5.1.3: How the interview was undertaken

In order to elicit information about the entire facilitation experience, interviews were undertaken as a single event a year after the final GSFCH workshop. This represented the end of the two-year GSFCH programme.

A decision was made to undertake one-to-one interviews. These would allow detailed exploration of the external facilitator’s experience of providing a specific approach to facilitation to each nursing care home they were involved with and their opinion of how this worked in practice. It also ensured there was an option to probe for detail and clarification. As the external facilitators came from a widely distributed area and often covered more than one nursing care home, a flexible approach to undertaking one-to-one interviews was required. Telephone interviews were offered as well as face to face interviews. There are reported disadvantages of undertaking telephone interviews, such as difficulty in building up trust and rapport and gaining the participant’s full attention (Hughes 2009). It was hoped that such difficulties would be minimised, as relationships with each external facilitator would be established as they submitted their Facilitation Activity Log during the two-year study.

One interview was held with each external facilitator. If the external facilitator had worked with more than one nursing care home each home was specifically discussed in turn. The external facilitators were all asked to give permission to record their interview on a digital voice recorder.

5.5.2: Surveys

Surveys are described as the method of choice to answer descriptive qualitative research questions and to explore association between measurable variables (Green and Thorogood 2005). They enable the collection of data from a wider audience than is possible with interviews, the collection of the same data from all participants and are more economical to administer. Surveys do however have disadvantages. There is a reliance on the participant being able to understand the question. There is also no opportunity to probe for more detail, to ensure a correct interpretation of what is written, nor to ensure that the person who completed the questionnaire is the same person who was issued it. Like interview data, surveys are an individual's unique account of their opinions, knowledge and/or behaviour (Polit and Hungler 1995). However, as with interviews, because they rely on self report the account provided may not be an accurate record of what actually occurred.

Prior to designing the questionnaires for this study, literature was reviewed on how to conduct questionnaires including: Edwards et al (2002); Bowling (2002); Bowling and Ebrahim (2005); and, more recently, Edwards et al (2009). The most common methods for delivery of surveys are electronic and postal. Within care homes both these methods present challenges. Care homes may have a lack of computer facilities and/or computer literacy amongst the staff (Hockley et al 2008) and undertaking

postal survey with care homes is reported to result in low response rates (and hence bias). Froggatt and Payne (2006) reported a response rate of 33% (n=81/248) which is similar to a large study undertaken much earlier by Sidell et al (1997) 41% (n=412/1000). However, a more recent study undertaken by the National Audit Office (2008) yielded only a 9.2% (n= 134/1410) response rate. These low response rates from postal surveys, and the limited access to computers in care homes, guided the decision to hand-deliver the questionnaires. Each questionnaire contained a personalised letter about the study. This method of questionnaire delivery was used by Mond et al (2004) who reported an increased response rate, and within two surveys described by Stover and Stone (1974) with respective response rates of 70% (n=211/300) and 84% (n=304/360).

5.5.2.1: The rationale for using surveys within this study

Surveys were used with two groups of participants:

1. The GSFCH coordinators
2. The nursing care home managers

Whilst two surveys were undertaken, the rationale for each of them varied. With respect to the GSFCH coordinators, each nursing care home could nominate two or three GSFCH coordinators to attend the GSFCH workshops. This meant there was a potential sample of 114 GSFCH coordinators. The potential sample size and their wide geographical distribution meant that interviewing them about their experience was not a viable option, in terms of time and cost. Surveys represented an ideal alternative method.

At the start of the study, the nursing care home managers pre-programme survey, gave baseline data about the nursing care home and their end-of-life care practice. Surveys were used due to the wide geographical location of the nursing care homes and the potential sample size (n=38). The nursing care home manager was then invited to participate in a second survey a year following the last GSFCH workshop, which gave comparative data. This second survey also asked specific questions about the provision and experience of receiving facilitation when implementing the GSFCH programme (Appendix Five).

5.5.2.2: The format of the survey

The GSFCH coordinator questionnaire: With no prior availability of a GSFCH coordinator questionnaire from previous GSFCH evaluations, a new survey was designed. The GSFCH coordinator questionnaire designed for this study was five pages long (17 items), despite the open ended nature of many of the questions (Appendix Six). The use of open questions within a survey allows exploration of topics where little is known, and where potential replies may be too numerous to pre-code (Bowling 2002). The concept of the GSFCH programme was relatively new. It was recognised that a lower response rate might occur by using open questions, as it required more effort from the participant. Following consideration, the decision was made to include within the questionnaire, some closed questions but mainly open-ended questions. This made the questionnaire longer, but the aim was to obtain a richness of data, rather than, necessarily, a high response rate. In addition emerging themes might then act as an aid to subsequent research in this area. In a health survey context, Hoffman et al (1998) found response rates were similar, for a four page (six item) questionnaire and a 16 page (76 item) questionnaire.

Following its development the GSFCH coordinator questionnaire was piloted with eight external facilitators who were familiar with the role of a GSFCH coordinator. They were asked to comment on its design. Minor changes were recommended and made. Ten *Phase 5* GSFCH coordinators (currently providing this role but not part of the study sample) then reviewed this questionnaire. These GSFCH coordinators suggested no further adjustments.

Nursing care home manager questionnaire: Previous evaluations of the GSFCH programme had used 'pre' and 'post' questionnaires with nursing care home managers (Clifford et al 2007). Clifford et al (2007) had undertaken an extensive evaluation of *Phase 2* the GSFCH programme. They gave permission to use their questionnaires. Upon their advice, the questionnaires were rewritten with a significant number of questions being removed. Their evaluation had shown specific questions to be redundant. Open ended questions were added relating specifically to facilitation. The final version of the 'pre' and 'post' questionnaires were circulated back to those who had designed and used the original version (Clifford et al 2007) and approval gained for its use. It was not piloted.

5.5.2.3: Validity, reliability, responsiveness, sensitivity and specificity of the different questionnaires used

Three non-validated questionnaires were used within this study; however, the validity, reliability, responsiveness, sensitivity and specificity of the questionnaires were considered but not formally tested as this was not an aim of this study (Bowling and Ebrahim 2005).

Validity: internal validity is an assessment of whether an instrument measures what it aims to measure (Bowling and Ebrahim 2005). The GSFCH coordinator questionnaire was new and at its development stage was tested in populations for which it was designed. It was found to have both face validity and content validity. The original nursing care home manager questionnaires had been extensively used before. Informal correspondence with those who designed and used it, suggested it had both face validity and content validity. The adapted questionnaire was reviewed and approved by those who had designed the original questionnaire. As it was not piloted, the validity of the new version of the questionnaire was unknown. The intention of the re-design of this questionnaire was to create a tool similar to that used in previous GSFCH studies, enabling comparability, not a new psycho-metric tool.

Reliability: refers to the reproducibility and consistency of the instrument (Bowling and Ebrahim 2005). Questionnaires in this study were used once with each sample to capture current opinion on the subject of implementing an intervention. The reliability (test-retest) of these instruments was therefore not directly assessed for this study.

Responsiveness: this refers to the ability of the instrument to respond to changes occurring in a population, or an individual, over time (Bowling and Ebrahim 2005). The GSFCH coordinators' questionnaire was new and provided no comparable data, as it was only administered once at the end of the study. The nursing care home managers' questionnaires were issued 'before' and 'after', the intervention. However, its responsiveness would be dependent upon each individual completing the questionnaire honestly, in the same way, and having an accurate understanding of the actual practice of end-of-life care provision in the nursing care home. Responsiveness

could have been measurable through the comparison of this data, where change was reported, with that from the CRCT where actual practice was recorded. However, such comparison is not part of this thesis.

Sensitivity and specificity: this refers to the ability of the instrument to identify individuals who have the target condition (sensitivity) and those who do not (specificity). The sensitivity and specificity of the questionnaires were considered in relation to the format of facilitation received in this study. Both the nursing care home manager questionnaire and the GSFCH coordinators' questionnaires had a question asking if they had a local external facilitator to assist them to implement the GSFCH programme. Additional questions about action learning were present on those questionnaires issued to the nursing care home managers participating in the *high facilitation* groups.

5.5.2.4: How the survey was undertaken

The GSFCH coordinator questionnaire: was given to each *Phase 6* GSFCH coordinator, a year following the final GSFCH workshop. Details of the GSFCH coordinators in post at the end of the study were provided by the nursing care home manager and external facilitator/s. Confirmation was also provided by the individuals themselves, when the questionnaires were delivered to the nursing care home, for them to complete. The questionnaires were delivered by hand and a variety of options were given for the return of the questionnaire:

- to complete it and return it immediately
- to return it by post (after they took a photocopy) in a stamped addressed envelope (provided)

- to return it via their external facilitator
- or, to complete it and keep it in the nursing care home for collection at a subsequent visit

Nursing care home manager questionnaire: were personally delivered to the nursing care home manager prior to, or immediately following the first GSFCH workshop. Prior to the visit, the nursing care home manager was phoned, and an appointment made. A written confirmation was posted which informed them the questionnaire would take 30 minutes of their time on the day to complete. I could be present whilst they completed the questionnaire, this was their choice. Thirty-eight questionnaires were issued.

The second survey ('post' questionnaire) was again personally delivered. The same options that were given to the GSFCH coordinators to return the questionnaire were offered. Any non-responders were contacted by phone a month later. Following this, they were sent a copy of the questionnaire, a stamped addressed envelope and a personalised letter.

5.5.3: Facilitation Activity Log

A third method of data collection was the Facilitation Activity Log that the external facilitators used. Information collected included details of the duration and format of the time they gave to the nursing care homes when helping them to implement the programme.

The keeping of diaries to record activities/events over a specified time frame is a well recognised research method (Bowling 2002). However the format of the diary varies. Green and Thorogood (2005) highlight the value of diaries as a resource, when investigating lived experience in anything other than the most recent history. Where diaries have been used as a research method to record activity, they are referred to as: activity diaries, work diaries, calendar diaries and time diaries. Whilst reflective diaries/journals have been used by health care professionals within research (Ortlipp 2008 and Borg 2001) very little literature reports on the use of other such diaries by professional participants, especially health care professionals.

Activity diaries: an activity diary is defined by Crosbie (2006) as a log of time allocation during the day focused on particular activities.

Work diaries: a clear definition was not sourced. Reference was made to their use within research studies, but within the literature they were not defined.

Calendar and time diaries: Time diaries provide a detailed, chronological record of events that occur during a specified 24 hour time period/s. The record is usually written very soon after the event, within a day or a week. In contrast, calendar diaries are used to record retrospectively, events that may have occurred months or years previously.

Activity diaries have been used in a hospital setting. They have been used to look at the work undertaken by hospital-based Clinical Nurse Specialists (CNSs), during a seven day period (Oddsdóttir and Sveinsdóttir 2011). The diaries had pre-coded responses where simultaneous multiple activities could be recorded. Very few responses were coded as 'other' and so the authors reported that activity diaries with

pre-coded responses worked well, though codes were individually interpreted. They detailed every activity, during a seven day period in 15 minute intervals. They were reported to be useful and easy to complete with only 4.7% of data missing. This may have occurred as it was senior nurses completing these diaries who valued research. They recorded a mean of four hours of research time within the week.

Whilst in a different context, Crosbie (2006) looked in detail at methodological lessons that could be learnt from using an activity diary over two days. She stated that a diary record of a participant's activity can either be self-administered (after an activity), or, researcher-administered (through observation or interviews). As with interviews and surveys, the record of activities is self-administered and so this recorded and reported account may not be an accurate record of what actually occurred.

Belli et al (2009) provided a comprehensive resource for the use of time and calendar diary methods and provided multiple examples of their use in practice. Within the other literature that was reviewed, a significant problem with the use of activity diaries was a high level of non-response. Campbell et al (2007) reported a study where so few workers completed a work diary, there was a lack of information about the active ingredient i.e. what the workers actually did. Crosbie (2006) used an activity diary, but only achieved a three per-cent response rate (n= 16/400). Due to this, the non-response participants were asked to complete the activity diary at the end of an interview which increased the response rate to 48% (Crosbie 2006). Belli and Callegaro (2009) reported that the use of a calendar diary, within an interview, resulted in more accurate and therefore better quality data.

Conclusions drawn from the literature therefore was that diary use with health care professionals was scarce and response rates poor. Response could be improved with hand delivery and collection, personal contact, and, recognising the activity diary as the main form of data collection. This information was used to guide the introduction of the Facilitation Activity Log to the external facilitators. Whilst it was a record kept over time, it was only a record about facilitation activity, not every activity. It recorded what the external facilitators actually did rather than what they had planned and intended to do.

5.5.3.1: Rationale for use of the Facilitation Activity Log within this study

As discussed earlier, interviewing the external facilitators was central to understanding the process and effect of providing facilitation to support the implementation of the GSFCH programme. The external facilitators' ability to recall information accurately during the two-year GSFCH programme, especially specific detail, was likely to have diminished. In order to answer the research question, knowledge of the external facilitators' actual behaviour throughout the two year period, was essential. Interviewing the external facilitators would not have provided this detail (Green and Thorogood 2005). Observation of the external facilitators' activity as a solution to reducing the external facilitators' recall bias was not a viable option, due to the length of the study and the number of external facilitators. A quantitative diary method offered an alternative approach and a means of obtaining complementarity about the concept of facilitation.

5.5.3.2: The format and use of the Facilitation Activity Log

The external facilitators were all told about the research study at the first workshop. They were informed that a detailed record would be needed of all the facilitation they provided. Whilst a structured format would allow easier interpretation and analysis of the record of facilitation through pre-coded responses, important elements might be missed. However, allowing participants to record events/activities in their own words would be time consuming to analyse and raised the risk that details could be wrongly interpreted. Agreement was made to send them an electronic document where they would record the date of contact, type of contact (phone, email or visit), purpose of contact, what occurred, time spent re contact and an action plan. The open structure ensured a record of all their facilitation interventions, as they perceived them. This formed the Facilitation Activity Log. It was agreed that this would be completed throughout the entire two year period that the GSFCH programme was to be implemented. At the end of the study, the interviews with the external facilitators allowed discussion of the use of the Facilitation Activity Log where clarification could be sought and details obtained of any omitted data.

5.5.4: Researcher's diary

I used a diary for data collection. This was a researcher's diary. It incorporated reflection but was not a reflective diary or a reflective journal. The completion of a reflective diary or a reflective journal is a research method often associated with, and encouraged within, qualitative studies to facilitate reflexivity (Ortlipp 2008 and Dowling 2006). Its purpose in this study was as a tool to create transparency. The use of the researcher's diary, in this way, is recognised by Borg (2001) and by Hughes (1996) who lists their uses as:

- A record of the history of the research study
- Material for reflection
- A record of the development of your own personal research skills
- Data on the research process

5.5.4.1: Rationale for use of a researcher's diary within this study

There were two main reasons for the use of a researcher's diary. Firstly I found myself in need of a system to help me manage a complex situation. At work, I was managing a large CRCT and within this, and at the same time, I was undertaking recruitment and data collection for this study. I needed a system for not only remembering and recalling events, but also a system that would both maintain a boundary and remind me of the connection between these studies. As Hughes (1996) suggested, the researcher's diary acted as a record of the history of the study; it also acted as a record of data collection. I recognised that the mixed methods approach taken might result in conflicting information. Whilst participants' accounts were all important and represented an accurate account of their story, the researcher's diary allowed an opportunity for me to construct my own account.

A second consideration was that as I undertook this study as a novice researcher, it was important for me to have an opportunity to record what I had learnt and also to have space to reflect on this learning. The use of a researcher's diary enabled this. As well as giving me an opportunity to reflect on the development of my research skills, the researcher's diary also helped me record and address the initial struggle and tension I had between my new role as a research nurse and my past CNS career. This tension arose from the new requirement to accurately document information, rather

than empower, share, help and educate. Because of this tension, I was very aware of the need to be totally transparent with the research process. This was important because in some circumstances, I would be the only person that visited the nursing care home, with a connection to the GSFCH programme.

5.5.4.2: The format of the researcher's diary

I kept two researcher's diary, one electronic and one paper. The electronic record began as a consequence of trying to record the events. The paper diary started later and was a tool to enable management of the research process and capture reflection on and learning from, the experience.

5.5.4.3: How the researcher's diary was undertaken

Both researchers' diaries were used intermittently and for very different purposes throughout the study. When the study started, the electronic diary was written after every visit or contact, to collect data. It acted as a record of significant meetings, as well as learning, and progress I made with the research study. Alongside this, the paper researcher's diary provided a space for me to record and to reflect on each visit or contact with the nursing care homes and the individual participants. Due to the sheer number of nursing care homes, and the time span of the study, small details would not have been possible to recall if it had not been for this process. This diary also provided me with an opportunity to internally discuss the experience of data collection.

5.6: Methods of analysis

The quantitative data was entered, stored and analysed using the Statistical Package for Social Science (SPSS) computer software package, version 18 (Bowling 2002). Qualitative data was entered into NVivo 9 and onto template coding tables (Crabtree and Miller 1999). As shown in Figure 5.1 the analysis of the data arising from each method occurred separately. It was following this initial analysis that integration of both data sets occurred.

5.6.1 Quantitative data analysis

This consisted of data from three sources:

- The nursing care home manager questionnaires
- The GSFCH coordinator questionnaires
- The Facilitation Activity Log

The quantitative data within the questionnaires provided basic demographic detail about each nursing care home and specific details about the nursing care home managers and the GSFCH coordinators. Analysis of this information was through the use of descriptive statistics in SPSS. SPSS enabled the approach to facilitation to be compared with information about the nursing care home for example; how many GP practices provided medical support for the residents; and, how many homes were accredited at the end of the GSFCH programme. It also allowed comparison amongst participants. The nursing home managers, for example, reported how long they had been in post and the GSFCH coordinators reported their attendance at the GSFCH workshops again in relation to the approach to facilitation.

The Facilitation Activity Log was intended to be flexible and to be individually constructed and submitted. However, due to the amount of data and the variety in format that this flexible approach encouraged, the data from the external facilitators was initially transferred across to a single sided summary paper record (Appendix Seven). Such a process had two advantages. Firstly, the sheet acted as a summary of the facilitation that was returned to the external facilitator to ensure accuracy. Secondly, it provided an opportunity to engage with, and have assistance from, a volunteer who was unfamiliar with the GSFCH programme. The volunteer had no vested interest in the study. The volunteer and I individually transferred each entry on each Facilitator Activity Log onto the summary paper record (Appendix Seven). Following this we met and any inconsistencies, in this transfer process, were then discussed and resolved.

Data from the summary sheets was then inputted into SPSS to be analysed. The use of SPSS allowed the data file to be split so analysis could occur in relation to the approach of external facilitation provided to each of the participating nursing care homes. Then the use of descriptive statistics enabled the median time, and range, of facilitation provided, from any source, within each of the facilitation groups to be identified. Detailed analysis was also possible for those homes with an external facilitator. With the data file split descriptive statistics enabled the frequency, as well as the duration of time, including mean and range, of facilitation to be determined in relation to its format.

5.6.2 Qualitative data analysis

The core component of the study was qualitative (Figure 5.1) consisting of data from:

- The external facilitators' interviews
- The nursing care home manager questionnaires (open questions)
- The GSFCH coordinator questionnaires (open questions)
- The researcher's diary

The external facilitator interviews were transcribed verbatim into individual Microsoft word documents. This was undertaken by an independent audio-typist and I then checked the accuracy of all the transcribed data against the original recording. The final transcriptions were imported to and stored within NVivo 9.

Analysis of qualitative data is noted to be a time-consuming, complex and iterative activity. There are many recognised approaches to such analysis (Spencer et al 2003), which involve data reduction, description and/or interpretation (Holloway and Wheeler 2002).

Data reduction was essential. This study had generated a considerable volume of qualitative data. In order to facilitate data reduction, template analysis was undertaken (Crabtree and Miller 1999). This approach to data reduction is reported to be both time-efficient and focused (Crabtree and Miller 1999). King (2004) reported it to be a system that is flexible, can be tailored to match requirements where the participant numbers are less than 30 and works well, when the analysis aim is to compare the perspectives of different groups of staff, within a specific context. In this study the perspectives of different groups of staff was important, in relation to the approach

taken when facilitating the GSFCH programme, (*high facilitation and action learning, high facilitation, local facilitation and no local facilitation*). This was achieved by the use of the following specific codes at the end of any quote where:

- *HFAL = high facilitation and action learning*
- *HF = high facilitation*
- *LF = local facilitation*
- *NLF = no local facilitation*

and

- M = nursing care home manager
- C = GSFCH coordinator
- F = External facilitator

Soft Systems Methodology (Checkland 1999) was introduced in Chapter three as a framework that enables an understanding to be gained of a situation under study before implementing change. It takes account of the organisation undergoing the change (**C**ustomer), the person implementing the change (**A**ctor), the process of change (**T**ransformation), any external worldwide influences (**W**orldview), management factors (**O**wner) and any environmental factors (**E**nvironmental constraints). The template enabled qualitative data including, but not only, that which was 'Actor' (facilitator) related to be organised and then interpreted. The initial categorisation of the qualitative data was into seven rather than six categories (one for each element of CATWOE with one additional category). The additional category was created to allow for any other issues not captured within the CATWOE framework and so reduce the risk of missing new, unanticipated insights. The template allowed

for storage, before coding and analysis, of any data that was identified as lying outside the six CATWOE Soft Systems components.

However, this study had produced a substantial amount of data. Prior to populating the CATWOE template a mind map was therefore drawn for each category. Mind maps were initially used to identify main factors in each category. An example of the mind map produced for the facilitators providing *high facilitation and action learning* is provided in Appendix Eight. Obtaining a detailed understanding of the external facilitation of the GSFCH programme (or the role of the Actor in CATWOE) was crucial to answering the research questions. This mind map was created from an initial reading of the facilitator interview transcripts, the nursing care home manager questionnaires, the GSFCH coordinator questionnaires associated with nursing care homes receiving *high facilitation and action learning*, as well as the researcher's diaries. Appendix Nine shows the initial mind map for environmental constraints along with its associated CATWOE category coding. The factors in each CATWOE category were initially populated using the mind maps. Sub-themes were then identified in the coded text. All the facilitator interview transcripts, the nursing care home manager questionnaires, the GSFCH coordinator questionnaires and the researcher's diaries were then read, and re-read, until there were no new supportive quotes to add into the CATWOE template. It was the immersion into, and crystallization of, the data within the factors imported from the mind maps into the seven CATWOE categories that identified the sub-themes.

Data was analysed both deductively (by the use of mind maps and a template that would create the higher order codes – factors) and then inductively (immersion and

crystallization within the factors that identified lower order codes – called sub-themes).

5.6.3 Integrating data

As this study used a mixed methods approach, there was a need to consider integration of all the data that was to be collected (Morse 2010). Integration is defined by Moran-Ellis et al (2006:51) as ‘the generation of a tangible relationship amongst methods, data and/or perspectives, retaining the integrity of each, through a set of actions specified by the research team, that allows them to ‘know more’ about their research topic’.

There are three recognised approaches for achieving this - the use of the triangulation protocol, following a thread and the use of a mixed methods matrix (O’Cathain et al 2010). A decision was made to use ‘following a thread’ to analyse the study data, because it acknowledged that different knowledge arises from different paradigms. However, it also respected the fact that the totality of this knowledge would be increased by interweaving the findings that emerge from both data sets. The study objectives included describing the experience of those providing and those receiving facilitation alongside identifying barriers and enablers when implementing the GSFCH programme. Separate initial analysis of the data would answer both questions. However, integrating the total data set through ‘following a thread’ (Figure 5.1) as part of the analysis, generated further knowledge by looking for evidence of resonance across findings (Moran-Ellis et al 2010). Storing the transcripts in NVivo 9 meant that when ‘following a thread’ the context of sub-themes could be easily identified within their source documents.

‘Following a thread’ resulted in the identification of a sub-theme in the qualitative data, which had not been identified during the initial analysis of the quantitative data. The Facilitator Activity Logs were reviewed to see if there was any evidence of this sub-theme. This information was not extracted during the separate quantitative data analysis. Initial analysis had only taken account of the components of the *high facilitation* or the *high facilitation and action learning* facilitation role. The new sub-theme was not such a component. Statistical tests were undertaken to determine if this sub-theme was significant (Fisher’s exact test) or associated with variables identified as important within the qualitative data.

The quantitative data in this study was from a small sample. This meant that when an additional sub-theme was identified through ‘following a thread’ undertaking standard statistical tests to better understand the available data was not possible. Bootstrapping offered a solution (Barber and Thompson 2000 and Thompson and Barber 2000). The process of re-sampling the original sample data resulted in a larger study population. Additional statistical tests could then be undertaken to determine if this sub-theme was associated with any other variables (logistical regression). This enabled the significance and relationship of these associated variables to be determined.

5.7: Rigour and quality

Assessing quality in mixed methods studies is important but how to do so is less clear than in straight quantitative and qualitative studies (O’Cathain 2010). In relation to the methods or the paradigms used, O’Cathain (2010) questions approaches that assess the quality of the studies, believing that there is more to a mixed methods study than the

sum of its qualitative and quantitative components. O’Cathain (2010) proposes a quality framework which includes eight domains:

1. Planning Quality
2. Design Quality
3. Data Quality
4. Interpretive Rigour
5. Inference Transferability
6. Reporting Quality
7. Synthesizability
8. Utility

These domains are comprehensive and come from a detailed review of the literature (O’Cathain 2010). For example, the domain reporting quality, in the dissemination stage of the study, contains the item reporting transparency. This relates to a study undertaken by O’Cathain et al (2008) where guidelines were developed following a review of mixed methods health service research, funded by the Department of Health for Good Reporting of A Mixed Methods Study (GRAMMS). These guidelines include ensuring the following are described:

- the choice of mixed methods as the research design
- the design in terms of its aim and methods
- each method
- where and how data was integrated and who took part in the process
- any limitations of using one method in association with another
- insights from integration

The use of the O’Cathain (2010) framework helped ensure that this thesis took account of rigour and quality in all domains (Table 5.4).

Table 5.4: Quality Framework as applied to this study (O’Cathain 2010)

Stage of study	Domains of quality	Items within domain	Evidence of item
Planning	Planning Quality	<ol style="list-style-type: none"> 1. Comprehensive and critical review of the literature 2. Rationale transparency 3. Planning transparency 4. Feasibility 	<ol style="list-style-type: none"> 1. Systematic literature review (see chapter four). 2. Explanation given in the research design. 3. Paradigm, design, data collection and plan for dissemination provided. 4. This study was feasible in terms of time, money and man power - it was occurring alongside a study that was already being undertaken.
Undertaking	Design Quality	<ol style="list-style-type: none"> 1. Design transparency 2. Design suitability 3. Design strength 4. Design rigour 	<ol style="list-style-type: none"> 1. Mixed methods design explained. 2. See above - number 2 (in planning stage of study). 3. Strengths and weaknesses of methods are all discussed within each of the method sections. 4. Methods follow the study design - qualitative and quantitative data is collected separately, analysed separately before being integrated.
Undertaking	Data Quality	<ol style="list-style-type: none"> 1. Data transparency 2. Data rigor/design fidelity 3. Sample adequacy 4. Analytic analysis 5. Analytical integration rigor 	<ol style="list-style-type: none"> 1. Methods are all described in detail, including their role, data collection and explanation of study sample, size and analysis given. 2. Methods were all implemented with rigour and fidelity considered. Any data cleaning was accounted for and transparency provided re grouping of participants against each approach to facilitation. 3. Explanation given re sampling and sample size. 4. Data analysis was appropriate to enable each research question to be answered. 5. Qualitative and quantitative data was analysed separately before it was integrated.
Interpreting	Interpretive Rigour	<ol style="list-style-type: none"> 1. Interpretive transparency 2. Interpretive consistency 3. Theoretical consistency 4. Interpretive agreement 5. Interpretive distinctiveness 6. Interpretive efficiency 7. Interpretive bias reduction 8. Interpretive correspondence 	<ol style="list-style-type: none"> 1. Data initially analysed separately ensured clarity about which findings emerged from each method. 2. Findings reported in association with inferences. 3. Inferences linked with current knowledge and theory. 4. Volunteer assisted in initial categorisation of the external facilitators quantitative data. Supervisors commented on sub-set. 5. All findings reported including any evidence of silence across other data sets when following a thread. 6. After the initial categorisation of the Facilitator Activity Log data one person undertook remaining analysis. 7. Inconsistencies explained. 8. The research questions were identified and so how well they were answered was addressed.
Interpreting	Inference Transferability	<ol style="list-style-type: none"> 1. Ecological transferability 2. Population transferability 3. Temporal transferability 4. Theoretical transferability 	<ol style="list-style-type: none"> 1-4. The findings would be transferable to other English nursing care homes. Whilst facilitation of change is relevant to many settings, transferability would be dependent on multiple aspects such as context/population.
Dissemination	Reporting Quality	<ol style="list-style-type: none"> 1. Report availability 2. Reporting transparency 3. Yield 	<ol style="list-style-type: none"> 1. See number 4 above in planning stage of study. 2. Insights from data integration are within the discussion chapter of this thesis. The remaining five GRAMMS (see 5.7) guidelines on reporting have all been covered in this chapter (O’Cathain et al 2008). 3. Integration of data by following a thread will clearly identify the whole being more than the sum of the parts.
Application in the real world	Synthesizability	15 quality criteria	The score that this study would achieve within a mixed studies systematic review could only be completed at the end of the study (Pluye et al 2009).
	Utility	Utility quality	Facilitation of the GSFCH is still encouraged but not mandatory - the study results will be usable in clinical practice. Use potentially increased by secondary data analysis against the CRCT data.

5.8: Ethical issues

This study did not commence until full ethical approval (REC reference 09/H0715/74) had been received (Appendix Ten). Ethical issues were a major consideration and included: informed consent; confidentiality; and, anonymity.

5.8.1 Informed consent

The process of consent was discussed within the recruitment section (see 5.4). In relation to informed consent, a presentation about both studies was undertaken at each site, and information sheets about the research distributed to and attached to notice boards on each floor of the nursing care home. The information sheets gave details about the study. They also provided my contact details, so that any staff member, including the GSFCH coordinators, could contact me via phone or email with any queries or concerns. These same details were provided on all questionnaires.

Data were collected from the nursing care home manager at the start of the study with questionnaires being completed at the same time as consent to participate in the study was given. However, the remaining data from staff in the nursing care homes was collected two years, later at the end of the study. Throughout the two year study period when collecting data for the CRCT, time would be spent informing any new staff about the study and the consent form re-signed, if needed. At the end of the study, it was ensured that the current nursing care home manager and GSFCH coordinators all knew about the study and had an opportunity to ask questions and to have any concerns addressed.

A notice of substantial amendment to the main Research Ethics Committee was required before the external facilitators were approached (see 5.4.6). This was necessary as when the ethics form was originally submitted, it had not been appreciated that external facilitators working in nursing care homes might be National Health Service employees.

The return of the nursing care home manager and GSFCH coordinators' questionnaires was taken as consent to participate in the study, as per ethics approval. It was intended at the outset to disseminate the results from the study. The nursing care home manager and their external facilitators were therefore asked to indicate on their consent forms, their decision regarding permission to use quotations from the questionnaires that were completed and the interviews that were undertaken, within publications and for teaching purposes at the end of the study. The external facilitators were additionally asked for consent to be digitally-recorded.

5.8.2 Confidentiality and anonymity

Confidentiality and partial anonymity was ensured throughout the research study. The lists containing the names and codes of the nursing care, the GSFCH coordinator and the external facilitator and their respective consent forms were stored in a locked filing cabinet in a locked room. Only I knew who had completed each survey. All returned questionnaires were coded, both in relation to the nursing care home and the participant and were stored separately, in a locked room. Data from the questionnaires was inputted onto a computer, which was only accessible via a password.

On the same day as an interview was undertaken, the data from the digital voice recorder was inputted into a password-protected computer and the original recording on the digital recorder erased. At transcription, all names and locations were removed and replaced by numerical codes.

5.9: Conclusion

This chapter has given an overview of the mixed methods approach to this research study. The particular challenges that this research design presents have been acknowledged. The recruitment of the study participants has been described and the data collection methods have been identified. Data analysis has been highlighted as a particular challenge with mixed methods and so the process and rationale given for the choices made in relation to this have been documented.

The results of the study have been divided into three separate chapters and are now reported. Each chapter relates to a phase of the GSFCH programme: the Preliminary Phase (Chapter Six); the Implementation Phase (Chapter Seven); and, the Consolidation Phase (Chapter Eight). These now follow.

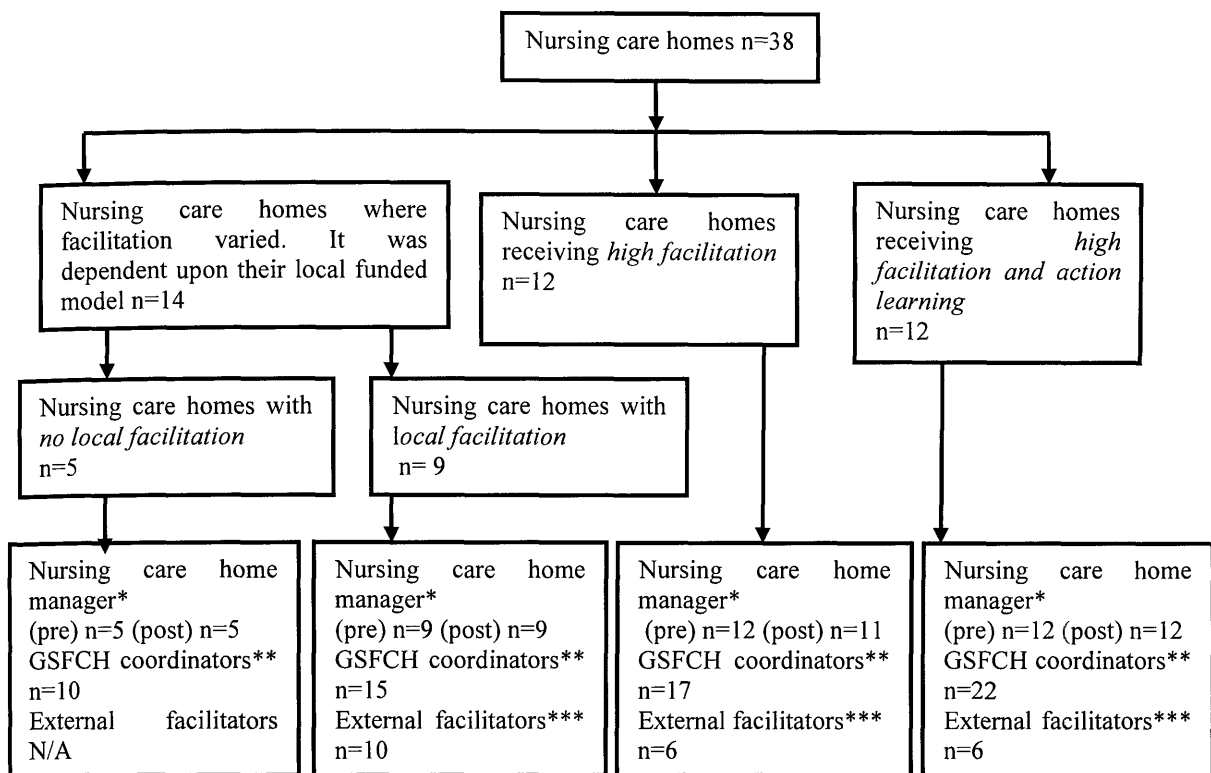
Chapter Six - The participants, their context and the findings from the Preliminary Phase of the GSFCH programme

After identifying the study setting and study participants, both the ‘worldview’ (the wider external context), the ‘environmental factors’ (the specific internal nursing care home context) are considered. The use of Soft Systems Methodology, as a framework for this study, identified these two factors as important to consider when initiating change. The ‘worldview’ and the ‘environmental factors’ influenced the implementation of the GSFCH programme across all three phases; the Preliminary, the Implementation and the Consolidation Phase. Taking these context issues into account, the experience of facilitation in the Preliminary Phase of the GSFCH programme is discussed.

The preparatory work undertaken by the external facilitators prior to the start of the first GSFCH workshop is reported. This included the external facilitators’ views on what they understood about facilitation, as well as how they gained information about the GSFCH facilitator role. Their knowledge and understanding but also their skills and experience of the GSFCH programme influenced their delivery of facilitation and consequently the nursing care home staffs’ experience of receiving it. Following this, the transformation factors (Checkland 1999) identified by all the study participants, that influenced this specific phase of the GSFCH programme are explored. These factors, where present, either acted as enablers or barriers.

6:1 Study setting and study participants

This study took place within 38 nursing care homes in south-east England. In relation to facilitation of the GSFCH programme the participating nursing care homes are responsible for finding their own facilitator. What had not been foreseen was that after the study started, some of the nursing care homes in the usual GSFCH facilitation settings, gained access to an external facilitator. As this study was looking at different approaches to facilitation of the GSFCH programme, this information led to a decision to divide this group into two groups: those who had an external facilitator (*local facilitation - LF*): and, those that did not (*no local facilitation - NLF*). The results of the study therefore reflect four, not three, approaches to facilitation of the GSFCH programme. Details of the 38 nursing care homes where the study participants were recruited from (nursing care home managers and GSFCH coordinators) or associated with (external facilitators), in relation to these four groups, are given in Figure 6.1. The response rate from all study participants was 100%.



* some nursing care home managers changed ‘pre’ and ‘post’ the programme and some were GSFCH coordinators

** the number of GSFCH coordinators a nursing care homes had, varied from zero to three

*** some external facilitators provided this role to more than one nursing care home

Figure 6.1: Nursing care homes and their associated study participants

6.1.1: The nursing care home managers (M)

Thirty-eight nursing care home managers took part at the start of the study. One nursing care home closed during the study period and so 37 nursing care home managers participated at the end. The nursing care homes had a stable internal management structure. Across all groups, the mean time as a nursing care home manager was in excess of five years and at least 57% (n=22) of the nursing care home managers had been in post for more than a year, at the commencement of the GSFCH programme. The specific time the nursing care home managers had worked within the

nursing care home context in any role varied from a mean of 11.8 years (*high facilitation and action learning* group) to 18 years (*no local facilitator* group).

6.1.2: The GSFCH coordinators (C)

The nursing care home managers had been encouraged to appoint at least two members of staff as GSFCH coordinators. They all achieved this, which meant when the study commenced, there was a total of 76 GSFCH coordinators implementing the programme within the 38 participating nursing care homes. At the start of the study the nursing care home manager took on the role of a GSFCH coordinator within 23 of the 38 nursing care homes. These were the key staff that the external facilitators needed to work alongside.

6.1.3: The external facilitators (F)

At the start of the study, 17 external facilitators provided facilitation of the GSFCH programme to 33 (87%) of the participating nursing care homes. Five (13%) of the nursing care homes had no local external facilitator (Figure 6.1).

6.2: Worldview: provision of external facilitation in relation to the nursing care homes external context

The participants acknowledged that the ‘worldview’ (external context) impacted on the implementation of each phase of the GSFCH programme. There was an acknowledgement that their practice within the nursing care home was dependent upon a wider societal change. This is demonstrated by a nursing care home manager’s comment that it was the national recognition of the success of the GSFCH programme, with publicised outcomes, that had engaged the nursing care home and motivated the staff:

'It is nationally recognised and allows us to improve the care provided to service users at the end-of-life, so that the care reflects the choices of the individual service user. It will also reduce unnecessary admissions to hospital.' [M.HF+AL5.002]

Also, as more nursing care homes undertake the GSFCH programme inevitably more staff will be exposed to its implementation:

'As more homes go through it and staff are exposed to the framework, then that process in itself might get easier. Because more people are going to be erm exposed to the GSF and how that works within organisations. And therefore you're not necessarily going to have to go back to the beginning if you've got staff...coming in that already have had that experience.' [F14]

With this, comes acknowledgement that whilst natural 'turnover' of staff within nursing care homes occurs, it may be that in time new staff will already have some experience of the GSFCH programme.

The *high facilitation* group were the only group to mention that implementation of the GSFCH programme was enabled when the external professionals working with the nursing care home staff had knowledge of it: *'Doctors in the community to be educated on GSFCH programme to make life easy.'* [C.HF4.003] Unless this occurred, the nursing care home were at risk of failing when medical advice or assistance was required: *'Nursing homes are alone. No back up team as like the hospice. Hopefully this is now changing.'* [C.HF7.028]

The view that nursing care homes worked in isolation extended into the staff belief about their participation in the GSFCH programme. One nurse manager voiced

concern that the GSFCH coordinators in the nursing care homes would not be able to network and support one another whilst implementing the programme. However, in practice this had not been the case:

'One manager told me before we started, erm, doing the Phase 6 that... I wouldn't be successful with the facilitator's meetings because no nursing home shared their practice or their knowledge or supported each other, and I was told that very categorically it wouldn't work and it wouldn't happen. Erm, but it has. So... there we go, just by, you know, starting it, it's worked.' [F2]

There was acknowledgement that the GSFCH programme was a nurse led initiative. However, to implement this fully into practice, the nursing care home needed to engage medical support which included GPs. In some cases the initial engagement was not always supportive. An aim of the programme is to reduce unnecessary hospital admissions. However, as one external facilitator stressed, the decision to refer a resident for a hospital admission sometimes came from the GP, not the nursing care home staff, although it was them who actually made the telephone call.

'... one of the PCT managers said to me: "Well [nursing care home name] are always calling 999." ... but often they've been told by their GP to call 999 if they suspect someone's got a PE or a DVT and needs some help. So, in a way they're in a Catch-22 with PCT are saying you're calling an ambulance too often. GPs are saying call 999, whereas if a GP called 999.' [F3]

The system underpinning access to GPs was also resource led. Another external facilitator noted that whilst at the moment the GPs were attending meetings, it was

because the PCT had offered them a financial incentive. She had concerns about the future:

'...so whilst, at one level, I might think, 'Oh, things are really gonna go forward,' come April 1st, that money might be pulled or certainly, perhaps not then, but certainly when the PCTs are disbanded, that money will probably be pulled and what will happen then?....You know? Unless we have totally, totally got their engagement at a psychological rather than a financial level, we'll be stuffed...' [F16]

There was an acknowledgment that 'worldviews' change over time. Previously residents did not die in nursing care homes:

'It's interesting that all of a sudden people are interested in where people die because initially, erm...they would have got smacked on the wrist, because (the care home regulatory body) would smack you on the wrist if too many people died in your care home.'[F11]

This acknowledgement is important. The GSFCH programme was intended to enable the staff in nursing care homes to develop the skills to meet the needs of their residents at the end of their lives. However, the nursing care homes are part of a wider community and to do this they require the support of the wider community including specialist health care professions, their GP and their regulatory board.

6.3: Environmental Factors: provision of external facilitation in relation to the nursing care homes internal context

A number of internal environmental factors were acknowledged to have had an impact, on every stage, of the of the GSFCH programme within the nursing care home. These were outside the control of the external facilitator and the nursing care

home staff and included the size and the structure of the nursing care home. Awareness and knowledge of these factors enabled the external facilitator to help the nursing care home staff find creative solutions. The influence of these two factors is described in turn.

6.3.1: The size of the nursing care home

Within this study, the smallest nursing care home had 22 beds and the largest 160 beds. It was often the extreme ends of this spectrum where size was indicated to be either an enabling or challenging factor, when implementing the GSFCH programme into practice.

Positive comments were made in relation to a nursing care home being small (Table 6.1). However, there were also challenges identified when a nursing care home was small.

Table 6.1: Internal context: enabler or barrier to implementing the GSFCH programme

Identified to be important when implementing the GSFCH programme	Act as an enabler if they are in practice during implementation of the GSFCH programme	Act as a barrier to the implementation of the GSFCH programme
<p>Understanding the internal context</p> <p>Size of the nursing care home</p>	<p>'I think it seems to be more easy to implement in a, in smaller care environments, because the information can be spread amongst smaller amounts of people...' [F11]</p> <p>'... because its purpose built it's ideal. We've got the space to set things up to have the meetings...And they've got space outside where they've made the erm remembrance garden.' [F15]</p>	<p>'...they've only got seven residents. They've had one death in there, since...we started the programme so you know...you can't get your teeth into anything because they don't have enough deaths, don't have enough symptoms to manage...It is by using these tools that they get the experience...' [F3]</p> <p>'But it is a big home and getting it, a message across to all the staff again and families we've had meetings with, the staff and families, which were well attended but as you can imagine...60 residents, there's 60 sets of families..' [F9]</p>
<p>Structure of the nursing care home</p>	<p>'I mean one of the good things that have happened, the whole place has been totally redecorated and it's absolutely stunningly beautiful now, so the actual environment is lovely to work in, erm, and I think that's boosted people, given them a little, you know, 'Actually, this is a fab place to work.' [F5]</p>	<p>'Dual residential getting them interested.' [M.HF+AL5.004]</p> <p>'I did not anticipate how disruptive noisy building work would be.' [C.NLF9,000]</p> <p>'I think also because it's two separate units and they are run separately, and they are actually physically apart, has been quite difficult.' [F8]</p> <p>'They're changing their identity but they're not able to change, they're not able to culturally change it, because their concept is so different and now they're suddenly...suddenly being full blown nursing home and they can't, the transition's been too much for them.' [F3]</p>

The only nursing care home that was shut during the study was a small nursing care home, which the owners believed was not financially viable. An additional challenge was difficulty in relation to available space to host training/hold meetings in. This was not a problem when the nursing care home was large (Table 6.1).

The greater challenge for small nursing care homes however related to gaining experience in end-of-life care as the nursing care home correspondingly had fewer deaths. A large nursing care home was noted to provide both opportunities and challenges for a greater variety of clinical experiences (Table 6.1).

The size of the nursing care home also had an impact on implementation. The external facilitators acknowledged the challenge of a larger nursing care home and facilitated this in a particular way. They recommended having monthly coding meetings on each floor in a large nursing care home instead of one monthly coding meeting for all residents in a small nursing care home:

'And I think that large homes, from what I've experienced, do have their own difficulties implementing anything because each, each floor is the size of one, perhaps one of our other nursing care homes... this is a five floored home...each floor runs separately, so I've learnt from the facilitation is that I have to, I manage each floor separately...they now have a weekly meeting and each floor.. So each has their own register... so I can get to know the staff on each floor as well - it's like a, each floor is like a separate unit.' [F3]

This way of implementing the GSFCH was initially very time consuming: *'... It's three separate coding meetings so that is three out of four weeks that I'm doing a*

coding meeting, let alone anything else.' [F2] They also recommended that where possible, each floor had a GSFCH coordinator and that in large nursing care homes, described by the external facilitators as over 50 beds, there should be at least three GSFCH coordinators.

6.3.2: The structure of the nursing care home

The structure of the nursing care home also needed to be acknowledged, when implementing the GSFCH programme.

6.3.2.1: Registration status

A number of the nursing care homes participating in the study were dual registered and so were able to provide personal care and personal care with nursing. Implementation within the same nursing care home then needed different approaches with some staff needing to develop good working relationships with the local district nurses. A number of external facilitators mentioned this amounted to implementing the programme within two settings, which presented additional challenges.

This was the same scenario for nursing care homes where the home was divided into different units in order to care for different client groups (Table 6.1). This was evidenced where a nursing care home had a separate palliative care unit. The focus on end-of-life care was in this unit, not throughout the nursing care home. During the study this unit was disbanded and the residents dispersed within the nursing care home. The external facilitators recognised that physical proximity did not equate to working cohesion and that the facilitation they provided needed to accommodate this.

An additional challenge to the implementation of the GSFCH programme was when the registration status of a home changed. One dual registered care home changed their registration to all personal care with nursing. This process involved additional change. Newly admitted residents had more complex need and the access to nursing support altered from the local primary district nursing service to one that needed to be provided in-house. The external facilitator noted additional internal change caused challenges when implementing the GSFCH programme (Table 6.1).

6.3.2.2: Internal stability

The GSFCH was implemented over a two-year period. During this period, a number of nursing care homes underwent refurbishment. Whilst the refurbishment was underway, people felt unsettled. However at the end, the investment in improving the environment boosted staff morale (Table 6.1). The challenge was to embed a new system when refurbishment of the nursing care home was occurring. In one nursing care home this took 18 months longer than expected.

6.4: Facilitators attributes

The external facilitators working locally to the Regional Training Centre worked across both the *high facilitation* and *high facilitation and action learning* groups. Their results are amalgamated and presented alongside those of the *local facilitation* group. A total of ten external facilitators provided facilitation to nine nursing care homes within the *local facilitation* group and seven external facilitators across the 24 nursing care homes in the combined *high facilitation* group.

The provision and experience of facilitation was influenced by the worldview and local environmental factors. Its delivery may have also been dependant on the way facilitation was defined and understood by each external facilitator. They were all asked to identify the core components of their role as GSFCH external facilitators.

The components that were identified included:

- being a support or resource
- empowering the nursing care home
- helping the nursing care home find their own vision
- active engagement by the nursing care home staff and themselves

In the groups providing *high facilitation*, additional comments regarding facilitation were made to those identified by the *local facilitation* and *no local facilitation* group.

These included:

- the concept of 'being present'
- creating a relationship:
- role modelling and
- sustaining practice

Facilitation was also dependent upon the external facilitator's terms of employment, educational background and their work experience (Figure 6.2).

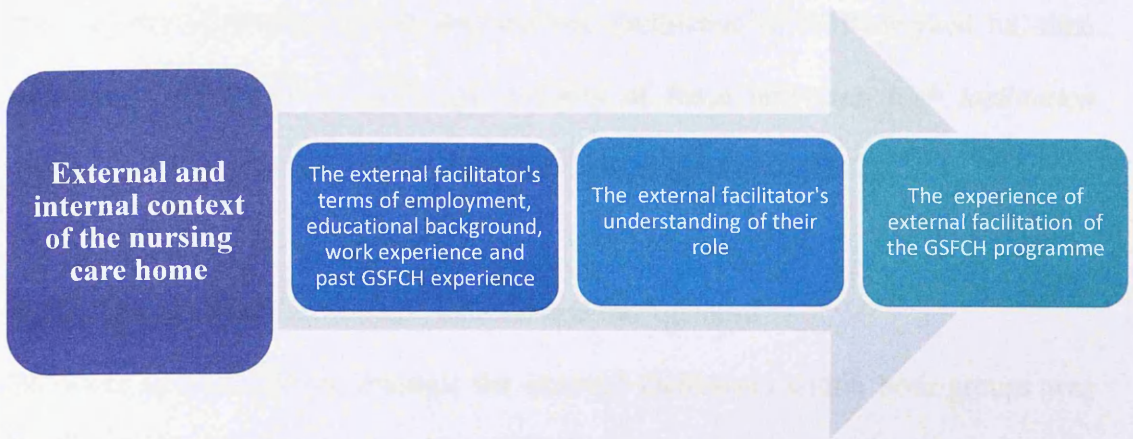


Figure 6.2: Experience of external facilitation in the Preliminary Phase of the GSFCH programme

6.4.1: The external facilitator's terms of employment

The sole job of the external facilitators working in the *high facilitation* groups was the provision of facilitation. This was not the case for any in the *local facilitation* group.

The ten external facilitators in the *local facilitation* group all had other responsibilities at work and this was reflected in the range of job titles that they held:

- End-of-life care facilitator care homes (with nursing) specialist team
- Clinical associate for the central GSF team and end-of-life care facilitator
- Facilitator for end-of-life care for care homes
- Clinical Nurse Specialist for older people for the care homes nursing team
- Clinical Nurse Specialist (care homes nursing team)
- Care specialist lead for end-of-life care (for care home provider)
- Nursing care home manager
- Regional head of operations (for a care home provider)
- Lecturer practitioner
- Practice and staff development manager for a care home provider

The majority of the *local facilitation* external facilitators (n=8/10) worked full-time with their different roles whilst the majority of those providing *high facilitation* worked solely as external facilitators in part-time employment n=5/7).

6.4.2: The external facilitators' educational background

The level of qualification amongst the external facilitators within both groups was similar (Table 6.2). More of the *local facilitation* external facilitators reported they had undertaken a short course in palliative care.

Table 6.2: Qualifications of the external facilitators

Qualifications of the external facilitators	<i>Local facilitation</i> (facilitated by 10 external facilitators)	<i>High facilitation</i> groups (facilitated by 7 external facilitators)
District Nursing	2	2
Palliative care - short course	7	2
Palliative care - degree	1	2
Educational	2	1
Other subject - diploma or above	3	2

Only two external facilitators within the *local facilitation* group had SPC work experience (Table 6.3). This contrasts with the *high facilitation* groups, employed by the Regional training Centre, where all external facilitators had SPC work experience. However, local external facilitators had more varied work careers.

The external facilitators in each group had many years of work experience. All trained within the UK and had been qualified for at least 18yrs (range 18-40). In the *local facilitation* group, the median time since qualification was 29.5yrs (range 18-31) and in the combined *high facilitation* group was 33yrs (range 18-40).

Table 6.3: Past employment of the external facilitators

Past employment	<i>Local facilitation</i> (facilitated by 10 external facilitators)	<i>High facilitation groups</i> (facilitated by 7 external facilitators)
Older people	4	0
Nursing care home manager	5	0
Management role (but not in a nursing care home)	5	4
Specialist palliative care (SPC)	2	7
Community	7	7
Teaching Post	3	0

6.4.3: The external facilitators work experience

In terms of past employment, all the external facilitators providing *high facilitation* had worked within the community in a professional background (for example district nursing) as had the majority of the *local facilitation* group (70%). Past employment of the external facilitators in the *local facilitation* group was more varied (Table 6.3) and incorporated working with older people, being a nursing care home manager and teaching.

The external facilitators familiarity with, and experience of, the GSFCH programme was similar across both facilitation groups. Six external facilitators (60%) in the *local facilitation* group had prior experience as a GSFCH external facilitator. This was also the case for four (57%) of the external facilitators within the *high facilitation* groups.

6.5: The external facilitators' preparatory work

The external facilitators undertook preparatory work, prior to the first GSFCH workshop starting. The outcome of this work impacted on the experience for both them and the nursing care homes they were involved with, as it shaped the format of the facilitation that was provided. It included identification of the role and consideration of their personal level of experience and expertise in such a role.

6.5.1: Establishing the external facilitators' role

The core elements that the external facilitators collectively reported were: provision of support, advice, guidance and helping others to avoid problems; active work; and, inspiring a vision for change. There was also recognition by some external facilitators from the start of the programme that 'one model will not fit all' and that the ultimate outcome of their role was the nursing care home taking on responsibility for the GSFCH programme, in a way that suited them.

Whilst there was some common agreement around the core elements of facilitation, there was greater disparity in how preparation for this role occurred in practice. As the nursing care homes in both the *high facilitation* groups were part of the CTCT the format of facilitation they provided was prescribed ahead of the GSFCH programme commencing with a proactive style. This was unlike the experience of the external facilitators providing the *local facilitation* approach, who reported struggling to identify their facilitation format. This was for a number of reasons. Firstly, there was no system in place (outside the Regional Training Centre) that linked information about nursing care homes commencing the GSFCH programme with local external facilitators. In the *local facilitation* group, this was described by one external facilitator as finding out by chance:

'...the first I knew about them (the nursing care home) being on the Gold Standard was when I got a letter from you (the researcher), because (name given) was very much on our patch, it was on my patch, this was the patch I covered.' [F11]

This meant that opportunity to work with the nursing care homes in the Preliminary Phase of the GSFCH programme had been missed. Raising awareness of the GSFCH programme within and out with the nursing care home is important, and three months of the GSFCH programme are allocated to this stage. The external facilitator really felt a missed opportunity; *'...had...we known that nursing care home (name given) was going to be coming onto the pilot, erm, I think...there would have been more input at an earlier stage, and specifically with the managerial team.'* [F11]

Secondly, there was a sense within the *local facilitation* group that the external facilitators did not perceive themselves, or chose not to describe themselves, as, providing a specific GSFCH external facilitator role *'we're none of us are specifically GSF but we're end-of-life facilitators.'* This lack of engagement with the concept of being a GSFCH external facilitator may have arisen because of the uncertainty of what they should be doing. A number of the external facilitators providing the *local facilitation* approach reported that they were uncertain of their role and responsibilities (see Box 6.1).

Box 6.1: External facilitators' summary of their role

They had tried to find out but no information was available

'...I've actually found it quite difficult actually with the GSF because there's not very much information that facilitators actually get...There's not really sort of a guidance pack for facilitators.' [F17]

There was a sense of feeling 'lost' in the role that they needed to provide:

'Yeah, some information of, yeah,...what am I meant to be...facilitating them to do?...I wasn't even clear what Gold Standards were initially - well, apart from the GP perspective and what obviously I'd read, but putting that into practice...it's not like I'd gone to a course for facilitators for Gold Standards and this...is what you should be doing.' [F10]

*'...I think it's difficult to know how much is involved or how much you **should** get involved. I think when you're doing another job and you're just supporting the home sort of ad hoc really, as and when they need you. I think it would be nice to have a bit more clearer guidance about what is expected and how much input.'* [F15]

It may be that as facilitation was not the dedicated main role for any of the external facilitators providing a *local facilitation* approach, the lack of clarity and focus meant they did not have to accept responsibility or accountability for this role. External facilitators in this group had other responsibilities and it may be that their performance was judged on their performance in these other core aspects of their role and not on their facilitation of the GSFCH programme.

6.5.2: Preparing for the external facilitation role

The external facilitators made various preparations for their role. As was evident from section 6.5.1, the degree of experience that external facilitators had varied. Some were new to the role, whilst others were experienced.

6.5.2.1: External facilitators new to the role of facilitation

One external facilitator who was new to post of external facilitation in the *local facilitation* group, recognised she was learning from a nursing care home manager who had undertaken the programme before. However, the nursing care home manager's learning was from the experience of a GSFCH coordinator of a previous programme, not as a GSFCH external facilitator. A member of the nursing care home staff was in fact teaching the GSFCH programme to them:

'I've found this time round [nursing care home manager] has probably been more of a support to me, showing me what needed to be done, rather than me supporting her. So I've been very lucky to have her support me.' [F15]

In the *local facilitation* group, there was also evidence that the external facilitators found accessing support challenging. The feeling for one external facilitator in particular was that of role isolation, which seemed irresolvable.

'...I haven't had support anywhere...So I felt quite isolated in what I'm doing, even my manager,she's not done that role, so ... there's no guidance... I did try and link up with other facilitators, erm, but it's quite difficult 'cos there isn't actually that many around...So I felt quite isolated from that perspective.'

[F10]

In preparation for her role this same external facilitator mentioned contacting the central GSF team to source information about her role, but failed to get any response from them. Instead of perusing and resolving this, she seemed resigned to this and therefore was learning through personal, rather than others' experience: *'So it's a bit like, a little bit like being a little...don't know, (chuckles) just learning as you go along really, isn't it?'* [F10]

This was not reported by any of the external facilitators in the *high facilitation* groups; possibly this was because they were based in an office together in the Regional Training Centre and were supported by each other.

There was recognition amongst the external facilitators in the *high facilitation* group that they might not know all the answers. As with the external facilitators in the *local facilitation* group, some were new into post. However, unlike the external facilitators *providing local facilitation*, they had joined a GSFCH external facilitator team and so learnt from those experienced at providing this specific role:

'I mean I've learnt quite a bit from F12 in terms of managing, organisation and things, you know, that whole thing of making six months of meetings and knowing why you're going in and what you're going for and all that.' [F16]

6.5.2.2: External facilitators with previous experience of a facilitation role

Some of the external facilitators providing *local facilitation* had been in a facilitation role before and were able to use previous experience to help them in their current role: *'... using your, your previous experience to help, erm, and identifying problems that we, we had here and trying to avoid them having the same problems.'* [F8] This took different forms.

One external facilitator providing *local facilitation*, learnt from her past experience that the GSFCH workshops as essential; so in this study she attended all four. No other external facilitator within this group reported doing this. For another, in a previous home when the nursing care home manager left the home implementing the GSFCH programme had failed to occur. Faced with this situation currently, she believed as it had not worked in the past, it would not work now:

'...I'd seen this before, erm, in another home where, erm, the manager's left and, as much as you try and go in and you support them with the GSF, they're, they're just so up to their necks in everything else that's happening that they don't really engage very much, so...I don't see... what else I could have done really.' [F17]

A number of the external facilitators within the *high facilitation* groups, had previously undertaken this role with nursing care homes attending earlier phases of the

GSFCH programme. Like F14 in the *local facilitation* group, they had learnt from this prior experience and indicated they used learning from past experiences to shape their provision of facilitation in their current role. Past experience really shaped the facilitation that F1 and F16 subsequently provided (Table 6.4). There was evidence of them actively working with the nursing care homes, to help them integrate the GSFCH framework into place.

Table 6.4: Past experience shaping current external facilitation role

Role of an external facilitator	Supporting comments
Arranging separate debriefing sessions	<i>'The thing that I'd done....that didn't work was I've always tagged on, initially tagged on the debriefing the SEA [Significant Event Analysis] to the end of the... or the beginning actually usually, of the, erm...coding meeting. And I'm not gonna do that with any of my Phase 7 homes because I just don't think it works...it would get forgotten or get left out or be rushed.'</i> [F16]
Giving time frames and objectives	<i>'...I've changed in that, erm, goal-setting with them, erm, and actually, (pause) you know, trying to give them some objectives and some timeframes so that things don't just wander off. Erm, I've been more firm with them...whereas before, the first phase, I was very much tiptoeing around.'</i> [F1]
Having coding meetings on each floor (for those nursing care homes with more than one floor)	<i>'...the other thing that I would do which I didn't do at HF+AL11...I think there's a lot to be said for having coding meetings on each floor because I think then you're much more likely to get the quiet HCAs.'</i> [F16]
'Being present'	<i>'...every time I left the care home I would set the next date, so it had to be, erm, giving them time to do what we'd planned for them to do, erm, and I would try and say to them, How long do you think it'll take you to do this? And I'll come back then'</i> [F1]

An experienced external facilitator used her experience in the Preliminary Phase to change how she provided this role. This included using tools believed to be more helpful than those recommended by the central GSF team: *'...the other thing I feel quite strongly about now is that...I wouldn't show, I would refuse to show the GSF DVD, 'cos I actually think it puts people off, I think it's so dreadful. The 'What do you see?' DVD gives far more, erm...about what really matters, I think.'* [F16]

6.6: Factors impacting on the Preliminary Phase of the GSFCH Programme

The GSFCH coordinators, nursing care home managers and external facilitators identified a number of factors that impacted on this phase of the GSFCH programme. From this qualitative data analysis, two main factors were identified as important in the Preliminary Phase of the GSFCH programme. These are:

- the level of preparedness for change in the nursing care home
- having a reason to undertake this work

Figure 6.3 depicts these two factors alongside their sub-themes along with the worldview and environmental factors as previously described.

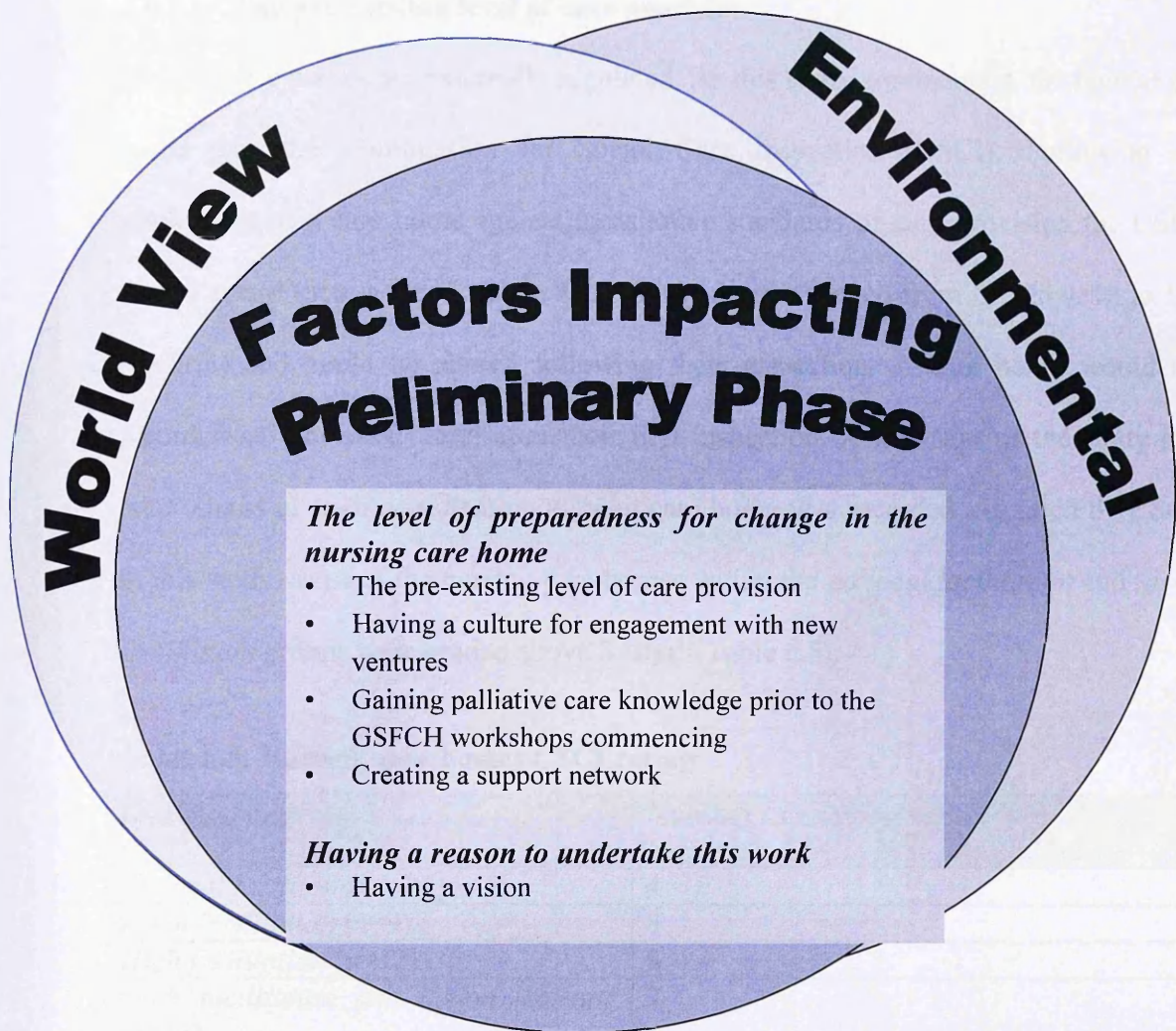


Figure 6.3: Factors impacting on the Preliminary Phase of the GSFCH programme

6.6.1: Level of preparedness for change in the nursing care home

There were four sub-themes identified that related to the level of preparedness for change in the nursing care home:

- the pre-existing level of care provision
- having a culture for engagement with new ventures
- gaining palliative care knowledge prior to the GSFCH workshops commencing
- creating a support network.

6.6.1.1: The pre-existing level of care provision

Nursing care homes are externally regulated. As this study commenced, the regulatory board was the Commission for Social Care Inspection (CSCI). Following an assessment of a care home against measurable standards of care provision the CSCI would award them a 'star' status. This rating scheme ranged from '0' (lowest) to '3' (highest) and could be altered following their inspection. A care home would be recorded as 'not rated' until after their first inspection. At the start of the study the 'star' status of each participating nursing care home was recorded. As rated by CSCI in this study, most of the nursing care homes within the *no local facilitation* and *local facilitation* groups were graded above 2 'star' (Table 6.5).

Table 6.5: Nursing care homes CSCI rating

Facilitation group	Number of nursing care homes achieving CSCI 'star' status 2 or 3
<i>No local facilitation</i> (n=5)	4
<i>Local facilitation</i> (n=9)	8
<i>High facilitation</i> (n=12)	8
<i>High facilitation and action learning</i> (n=12)	7
TOTAL: 27/38	

Before they started the GSFCH programme, GSFCH coordinators in the *local facilitation* group were the only group to acknowledge that the high standard of care within their nursing care home, was what enabled them to put the programme into place (Table 6.6). However, one external facilitator's identified that this enabler had in fact acted as a barrier in another nursing care home (Table 6.6).

Table 6.6: Enablers or barriers when starting the GSFCH programme

Identified to be important before commencing the GSFCH programme	Act as an enabler if they are in practice prior to starting the GSFCH programme	Act as a barrier to the implementation of the GSFCH programme
Level of preparedness for change in the nursing care home	<p>'I do think we were already delivering resident-focused care, in many ways in line with the GSF... Good relationships already with carers, residents and relatives.' [C.LF2.000]</p> <p>'Yes, it was, it was already a home that delivered good care, erm, but the lovely thing is they were open to learning other skills as well, and particularly about end-of-life care.' [F5]</p> <p>'I think it helped them (GSFCH coordinators) to know a little bit more about what end-of-life care was going to be about.' [F3]</p>	<p>'Erm, but I'm not sure – I think they think they do it very well, and it's quite hard to get beyond that, too actually look at actually it's not so good. Erm... it's quite a struggle in there, I have to say. It's hard work.' [F2]</p> <p>'I think nurses have been there for a long time, they've got away with a lot, and it's almost impossible to get them to change their way of thinking....' [F2]</p>
Having a culture for engagement with new ventures		<p>'Difficult at times when RGNs have no experience with palliative care. I was a little shocked at the first meeting when we had to raise hands to let you know how many nurses had seen a dead patient. ¼ did not put their hand up.' [C.HF7.028]</p> <p>'I think there's no, none of the staff, qualified or not, had any particular palliative care experience.' [F9]</p>
Gaining palliative care knowledge prior to the GSFCH workshops		
Commencing and creating a support network	<p>'Erm they met with other co-ordinators who were in exactly the same situation as they were so... they were sort of able to have a support system for themselves... So the co-ordinators knew each other before they attended the first workshop and I think that really helped.' [F3].</p>	
Having a reason to undertake this work	<p>'Already a 3* rated home by CQC [Care Quality Commission] this will be helpful in maintaining this rating and hopefully be beneficial when marketing the home vs local competitors.' [M.LF2.002]</p>	<p>'...She, she doesn't know. I don't, I just think there's a lot of naivety out there about how they're going to be doing this programme.' [F3]</p>

The coordinators and nursing care home managers in the *no local facilitation* and *high facilitation* groups made no reference to the pre-existing standard of care in their nursing home or prior experience of undertaking the programme. However, the external facilitators, unlike the nursing care home managers and GSFCH coordinators, did recognise the pre-existing high standards of care within some of their nursing care homes.

6.6.1.2: Having a culture for engagement with new ventures

The pre-existing high standards of care within some of the *high facilitation* nursing care homes were reported by the external facilitators as associated with the nursing home staff ability to learn (Table 6.6). For some nursing care homes, a pre-existing level of high quality care helped them to implement the GSFCH programme. However, where there was a lack of capacity to learn in a nursing care home that had a pre-existing high standard of care, it acted instead as a barrier to the implementation of the programme (Table 6.6).

6.6.1.3: Gaining palliative care knowledge prior to the GSFCH workshops commencing

One of the challenges when starting the GSFCH programme in some of the nursing care homes was the staff's lack of palliative care experience. This lack of experience included staff confidence and skill to provide palliative care which presented additional challenges to implementing the GSFCH programme (Table 6.6).

There were concerns expressed by the GSFCH coordinators about staff's experience and confidence in managing dying and death. The *high facilitation* approach recognised this and had taken steps to introduce basic concepts of palliative care, prior

to the GSFCH workshop. This resulted in participating nursing care homes in the *high facilitation* groups all having access to the Macmillan ‘Foundations in Palliative Care for Care Homes’ training, prior to the first GSFCH workshop.

In all but one nursing care home, the GSFCH coordinators welcomed the opportunity to attend the Macmillan ‘Foundations in Palliative Care for Care Homes’ training (Table 6.7). The non-attendance of one nursing care home only occurred because the decision of the nursing care home to participate in the GSFCH programme was made as the workshops started. They therefore missed the opportunity for the Macmillan ‘Foundations in Palliative Care for Care Homes’ training, provided as part of the Preliminary Phase.

Table 6.7: The Macmillan ‘Foundations in Palliative Care in Care Homes’ Training

Facilitation group	Number of nursing care homes where the GSFCH coordinators received Macmillan ‘Foundations in Palliative Care for Care Homes’ Training
<i>No local facilitation</i> (n=5)	1
<i>Local facilitation</i> (n=9)	2
<i>High facilitation</i> (n=12)	12
<i>High facilitation and action learning</i> (n=12)	11

One nursing care home manager in the *no local facilitation* group independently saw the need for palliative care training. She implemented the training within her own nursing care home, during the final part of the programme (the Consolidation Phase) rather than the Preliminary Phase. This was the only nursing care home in the *no local facilitation* group to report doing this (Table 6.7).

6.6.1.4: Creating a support network

As well as its educative role, attendance at the Macmillan ‘Foundations in Palliative Care for Care Homes’ training resulted in the formation of a support network so the external facilitator believed the perceived benefits of participating in the training went beyond knowledge exchange (Table 6.6).

6.6.2: Having a reason to undertake this work

One sub-theme was identified that related to having a reason to undertake this work, namely having a vision. The decision for the nursing care home to register to undertake the GSFCH programme was taken at senior management level. They saw potential future value for the home as a consequence. Whilst this was mainly the nursing care home managers, in some instances it was the nursing care home owners:

‘We have been interested in the programme for some time and had started to take part with the help of the local hospice. [the care home owner] then informed us that we would need to be on a programme that was accredited.’
[M.LF10. 000]

The nursing care home managers’ rationale and aims for undertaking the programme varied. One nursing care home manager made reference to the role commissioners played in her decision to register for the GSFCH programme. The London Procurement Programme would only fund places for continuing care residents in accredited GSFCH homes, so undertaking this programme was also viewed as a future investment (Table 6.6).

Several nursing care home managers had registered the home to undertake the GSFCH programme, anticipating benefits for themselves, staff, the residents and their relatives. Their vision was to improve the nursing care home's ability to deliver quality end-of-life care:

'We would like to have the skills and confidence to start discussing service user's wishes in a timely manner, in order that end-of-life care is planned appropriately, meeting the needs of the individual.' [M.HF+AL5.002]

6.7: Conclusion

In the Preliminary Phase of the GSFCH programme, the external facilitators undertook preparatory work for this role as well as preparation by the nursing care home staff. All the external facilitators brought their own unique experiences of facilitation and of the GSFCH programme, which shaped their individual practice. The facilitation they delivered, and therefore the experience the nursing care home staff received, was influenced by this.

There were a number of pre-existing factors identified that existed within, and between, the 38 participating nursing care homes at the commencement of the GSFCH programme. When present, these factors acted as enablers to the implementation of the GSFCH programme and when absent, formed a barrier. From these different individual baselines, the participants within, and those associated with the nursing care homes implemented the GSFCH programme. The next chapter details this experience.

Chapter Seven - The Implementation Phase: workshop one to workshop four

Throughout the Implementation Phase all the nursing care homes had access to facilitation via the Regional Training Centre. For 33 of these nursing care homes GSFCH facilitation was also provided by external facilitators working within the nursing care homes' particular regional area. The approaches taken by the external facilitator to deliver facilitation were identified during this phase and so the details are provided here. The approach taken did extend into other phases of the GSFCH programme. The experience of the external facilitators providing, and the nursing care homes experience of receiving, the style of facilitation associated with each approach is described.

Following on from this the factors the participants identified that enabled or acted as barriers to the Implementation Phase of the GSFCH programme are reported. The particular contribution of facilitation to the transformational process is accounted for (Checkland 1999).

7.1: The delivery of GSFCH facilitation

It was intended that, where present, the external facilitator would provide facilitation across the Preliminary Phase, the Implementation Phase and the Consolidation Phase of the programme. The two sources of facilitated support available to the GSFCH coordinators, were via this identified external facilitator (where present) and the Regional Training Centre. Facilitation was at its most intense in the first year, during the Implementation Phase (Figure 7.1 and 7.2). Details of the duration and the format that this facilitation took are as recorded by the Regional Training Centre and by the

external facilitator in their monthly activity logs. The total time of facilitation, provided from both these sources, is reported in relation to the approach of external facilitation provided to the nursing care homes: *no local facilitation*; *local facilitation*; *high facilitation*; and, *high facilitation and action learning* (Figure 7.1 and 7.2).

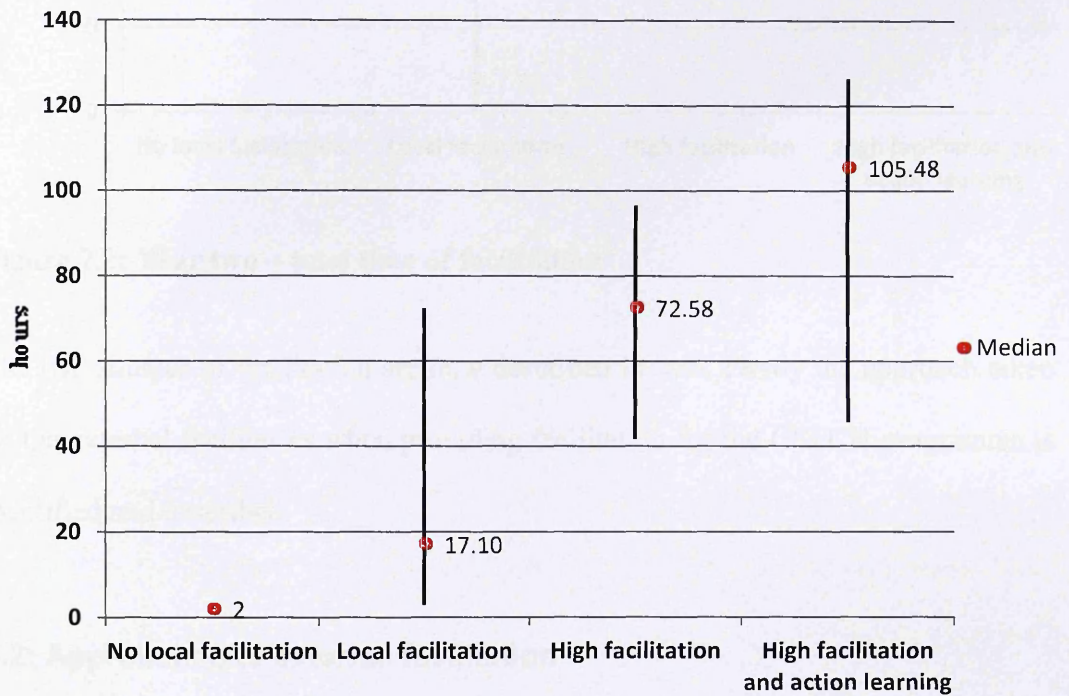


Figure 7.1: Year one - total time of facilitation

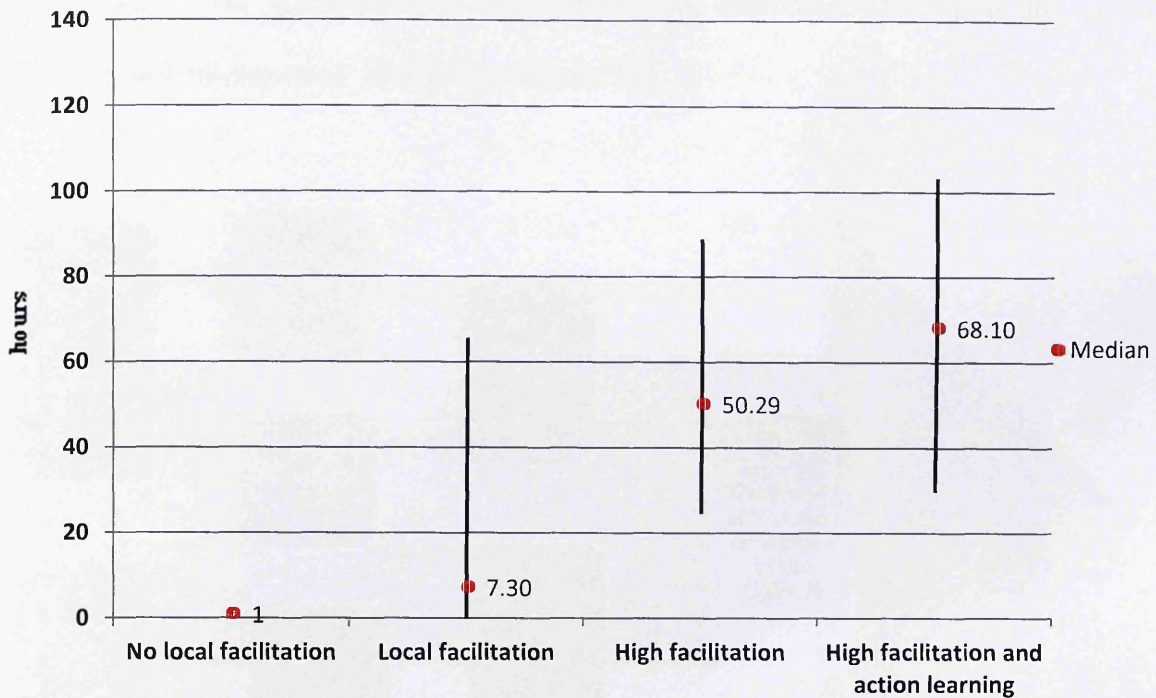


Figure 7.2: Year two – total time of facilitation

The two sources of facilitation are now described in turn. Firstly the approach taken by the external facilitators when providing facilitation for the GSFCH programme is identified and described.

7.2: Approaches to external facilitation

The experience of external facilitation, by a nominated external facilitator, was only applicable in three groups (the *local facilitation*, the *high facilitation* and the *high facilitation and action learning groups*). The facilitation provided was either not imposed ‘ad hoc’ (*local facilitation group*) or ‘prescribed’ (both *high facilitation groups*) (Figure 7.3).

In the *local facilitation* group, where a facilitation plan was not imposed, other factors acted to shape the format and therefore the experience of the facilitation that

was provided. Two approaches to facilitation were identified: ‘fitting it in’ and ‘as requested’ facilitation (Figure 7.3).

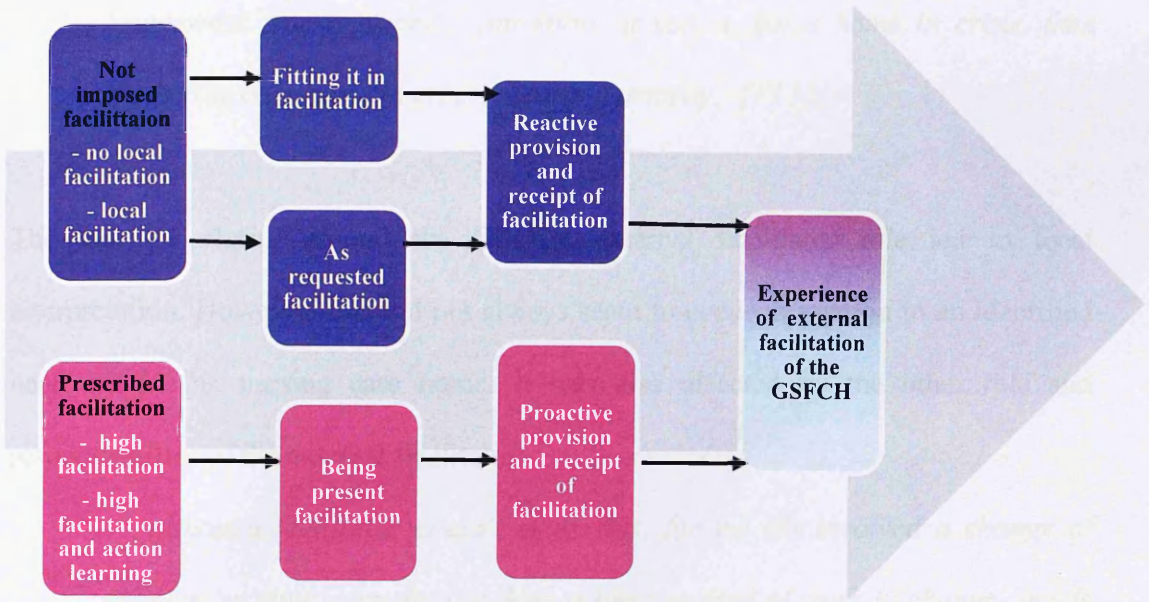


Figure 7.3: Experience of external facilitation of the GSFCH programme

7.2.1: ‘Fitting it in’ facilitation

The external facilitators providing *local facilitation* had multi-faceted roles, where facilitation was not the major concern/priority. They had often been asked to take this on, leading to conflict in time management between this and the other roles they then needed to juggle. ‘...It was something I was asked to do as a part of my job.’ [F8]

When facilitation was one aspect of a job, it was often seen as the least important. The focus of their time was on the elements of their main role, which were often their area of strength and the easier component of their role to fulfil. For example, one of the external facilitators in the *local facilitation* groups had education as her main role so the main focus of her GSFCH facilitation was education. A second example was where an external facilitator’s role was linked to a clinical role:

'I think because I was...doing, erm, a busy day job, the facilitation was very much an add-on to my then role, erm, and, you know, there was a lot of conflicts with priorities and things. And although the Gold Standards Framework was a priority, you know, if you've got a home in crisis, then that's (the care home in crisis) clearly a priority.' [F13]

The lack of clarity around the GSFCH external facilitator role led to local interpretation. However, this did not always seem to occur in relation to an identified need within the nursing care home. It was also affected by the other role and responsibilities of the external facilitator:

'...although facilitator doesn't mean this, for me it's involved a change of policies, writing manuals, I've done a huge amount of work to change-, made changes to our organisational (care home provider) policies and procedures as a result of this...' [F9]

The lack of clarity in how to provide facilitation, alongside the need to juggle time for this alongside their other roles, meant that the facilitation offered was what time permitted. Some of the external facilitators in the *local facilitation* group reported that they had linked their local nursing care homes together. However, unlike with the *high facilitation* local nursing care home network forums, where they were encouraged to meet as a way of supporting and sustaining change, this approach had been developed due to time pressures. In one locality, the facilitation role was part time. It did not feel possible to meet the nursing care home staff individually and so to save time, staff came to a central location:

'...the only way I could do it was to get all the homes together and just see where they are. ...I can't facilitate 10 of them...I connect in with them and sort

of have a catch up session on how they are, but that's just purely for my reporting.' [F4]

7.2.2: 'As requested' facilitation

More often than not in the *local facilitation* approach rather than building a relationship, the external facilitators relied on the nursing care homes to approach them for assistance. However, when the onus was left to the nursing care home to contact the external facilitator, it did not happen:

'It's very ad hoc; it's very... it's just whatever they want and whatever they need really... Cos that...yeah, cos that's the thing, I mean, you can't, you can't force yourself on people, can you? ...I've got to rely on you to get in touch with me and...consequently they haven't actually...' [F17]

7.2.3: 'Being present' facilitation

The third approach to facilitation was one of 'being present'. This approach provided proactive facilitation rather than reactive facilitation. However, how the external facilitators achieved this, including how they used the time when visiting the nursing care home, was individually interpreted. From their descriptions, the external facilitators provided different approaches to facilitation even though there was an underlying prescribed format.

In both the proactive facilitation groups, a *high facilitation* approach was imposed. The external facilitators were required to provide a previously defined, and agreed, format of *high facilitation* which included undertaking particular activities (Table 1.1).

Table 7.1 shows participation by the GSFCH coordinators in the two *high facilitation* groups of nursing care homes, in these intended activities, during the first year.

Table 7.1: Receipt of high facilitation by the GSFCH coordinators in the first year

Facilitation group	Two GSFCH coordinators appointed (n=24)	GSFCH coordinators received Macmillan 'Foundations in Palliative Care for Care Homes' training (n=24)	GSFCH coordinator had face to face contact with the external facilitator 2-3 times a month (n=24)	GSFCH coordinators implemented the LCP/ICP (n=24)
<i>High facilitation (n=12)</i>	12	12	9	9
<i>High facilitation and action learning (n=12)</i>	12	11	12	12
Total	24 (100%)	23 (96%)	21 (91%)	21 (91%)

The concept of 'being present' meant that the external facilitators could identify where the nursing care home needed help. One external facilitator set up a coding template for a nursing care home on the computer. Another recognised that a change in the approach was needed, when a nursing care home requested additional training, but was not able to implement it into practice. A third external facilitator noted few nursing care home staff attended training and rather than let it go, followed this up with the nursing care home manager. Providing this type of facilitation role took time, commitment and energy but 'being present' enabled them to give attention to detail and follow things through.

7.3: The relationship between the different approaches to external facilitation and the delivery of facilitation

The external facilitators earlier description of their role (see 6.4) was segregated into the three approaches to facilitation actually provided: ‘fitting it in’, ‘as requested’ and ‘being present’. The comparison between the external facilitator’s roles as they defined them and that delivered, as reported by all the participants, is presented over the page (Table 7.2). The way each of these three approaches to external facilitation, ‘fitting it in’, ‘as requested’ and ‘being present’, were delivered is further considered in 7.3.1.and 7.3.2.

Table 7.2: Descriptions of the external facilitators' role

External facilitators' description of their role	'fitting it in' and 'as requested' external facilitation External facilitators supporting comments	'being present' external facilitation	'fitting it in' and 'as requested' external facilitation What they actually provided (comments by all participants)	'being present' external facilitation
Support, advising, giving guidance and helping others to avoid problems	'...a supporting role I think more than anything.' [F15] '...enabling...guiding people... and...and identifying problems that we, we had here and trying to avoid them having the same problems.' [F8]	'a resource' [F4]	'it's probably been different for me this time round, being the first time because [nursing care home manager] knows far more than I do...I've found this time round [nursing care home manager] has probably been more of a support to me.' [F15]	'As one of the coordinators I felt so drained, stressed when we were starting the GSF programme but when the facilitator came to visit more often and explained things I was quite relieved.' [C.HF+AL2.001]
Empowerment so the nursing care home taking responsibility	'Enabling people to...achieve outcomes in a way that helps them understand and be able to work with a process. Rather than instructing somebody to do it, it's about enabling them to find their own way through.' [F13]	'enabling walking through the journey with them.' [F4] 'enabling care home staff. I think it's not going out and doing the work for them it's supporting them doing the work.' [F3]	'erm we don't need to pitch up and say to her 'We're going to come in at a regular basis, you know, we're going to come in once a month or we're going to come in every 6 weeks.' We come in as requested...' [F14]	'We had a facilitator who was very helpful and approachable. She became part of our team although sometimes she would give us the lead and we would continue in a way that suited us. The programme became ours as a team, she just helped us to keep on the right track.' [M.HF+AL2.000]
Active work by the external facilitator	'I would say it's supporting and encouraging, but you have to lead it, you have to take some control over it. I'm finding that, for me I've...organising workshops, organising meetings to get the staff on board with it...' [F9]	So not doing for them but doing with them and, erm, kind of a bit like, yeah, coaxing them, being behind them, mentoring them, pushing them forward, empowering them, encouraging them.[F1]	'She comes and checking our coding and ACP and best interest forms...' [C.LF5,077]	
Inspiring a vision for change	To...signpost people in the right direction [F10]	'...it, is empowering other people to do things, so to catch, to get, help them to be caught up in the...in the moment of how change can be brought about.' [F16]	'I did have an outside facilitator for support only. She didn't know much about GSF and, as I had followed the programme fully once before, I had much more experience and knew what I was doing...' [M.LF8,000]	'The outside facilitator has been hard working, efficient and knowledgeable. She has supported the home and GSFCH programme to the smallest detail.' [M.HF+AL8.000]

External facilitators' description of their role	'fitting it in' and 'as requested' external facilitation External facilitators supporting comments	'being present' external facilitation	'fitting it in' and 'as requested' external facilitation	'being present' external facilitation
Flexible - one approach will not fit all	'...I think a facilitator actively listens to what the person actually wants from them. They support rather than do...I don't believe in saying 'This is the way it should be done'. It's got to be that it's right for the people that are actually going to be doing it day in and day out. It's not got to be the F14 method.' [F14]		'...there is certainly some homes that I've said: "No, no. You're not, you're not ready yet." [F9]	
Being present		'So not doing for them but doing with them ...coaxing them, being behind them, mentoring them, pushing them forward, empowering them, encouraging them.' [F1]		'Visiting and coaching during coding meetings and debriefings.' [C.HF+AL9.001]
Creating a relationship		'I'm not going into routinely now but when I do go into them they've, they've always got something to tell me about Gold Standards Framework or end-of-life care or asking me a question about something that's going on and I do feel, you know, we, we develop a relationship with ...care homes...' [F3]		'Input from the facilitator has been excellent. All staff knew her and will ask questions.' [M.HF8.055]
Role modelling		'I think it's more about smoothing the way, encouraging, erm... teaching and describing, role-modelling - so many different sort of elements to it really' [F6]		

External facilitators' description of their role	'fitting it in' and 'as requested' external facilitation	'being present' external facilitation	'fitting it in' and 'as requested' external facilitation	'being present' external facilitation
		External facilitators supporting comments	What they actually provided (comments by all participants)	
Sustaining external facilitation		<p><i>'It always needs someone to guide it, fuss about it, worry about it, get it going, keep it on track.'</i> [F3]</p> <p><i>'and learned in a way that they can also hopefully pass those skills on to somebody else to keep the continuity and keep it embedded in the culture.'</i> [F13]</p>		<p><i>'The coordinators meet continually with other homes and GSF staff to prevent the lack of motivation creeping in and to remind us of the overall ethos of the Gold Standards.'</i> [C.HF+AL8.000]</p>

7.3.1: The delivery of ‘fitting it in’ and ‘as requested’ facilitation

There was little structure or regularity to the facilitation and it relied on the nursing care home staff requesting it: *‘F11 is available to meet with all the time if you ring and make appointment.’ [C.LF13.000]* External facilitator visits were reported to have occurred in relation to the GSFCH ‘coding meetings’ and the provision of education. Facilitation was not directed at empowering and role modelling by working alongside the staff in the nursing care home. It instead provided a form of monitoring (Table 7.2).

Not all GSFCH coordinators in the *local facilitation* group had face-to-face contact with the external facilitator. Where a GSFCH coordinator was the nursing care home manager, the facilitation was usually provided solely to them even if there was a second GSFCH coordinator. The second GSFCH coordinator reported that they were excluded from support by the external facilitator and described facilitation within the nursing care home as: *‘Meetings with [name] manager.’ [C.LF8.001]*

What was unexpected were the comments received from the *local facilitation* group who had an external facilitator but, at the end of the study, were not aware of it: *‘Had I of known the route I would not have commenced not having a facilitator.’ [C.LF10.00]* These nursing care homes had not got the partnership form of working with their external facilitators that the *high facilitation* groups had. This was the case in nursing care home LF10, as neither the external facilitator nor the nursing care home manager had changed during the two years: *‘To have regular support would have been beneficial-to ‘brain storm’ ideas and occasionally lessen ‘the load’.’ [C.LF2.001]*

When staff turnover occurred in relation to the nursing care home manager and/or the GSFCH coordinators, information regarding the GSFCH programme external facilitator was not passed on. This was the case in nursing care home LF03 where they had an external facilitator but the nursing care home staff reported in the study questionnaire that they did not. It would seem that as this information remained unknown, that the external facilitator had also not contacted them.

One nursing care home manager made the comment that facilitation was dependent upon the external facilitator's knowledge and expertise with the GSFCH programme (Table 7.2). What seems clear is that the definition of an external facilitator's role; 'support', 'empowerment' and 'vision' did not always translate into the facilitation that was reported as having been provided. This information was gained due to the systems based approach that was used in this study which encouraged more than one participant's perspective to be obtained.

7.3.2: The delivery of 'being present' facilitation

In contrast, the GSFCH coordinators in both the *high facilitation* groups had regular visits to the nursing care home. The external facilitators aimed to role model and empower the GSFCH coordinators to implement the GSFCH programme. The external facilitators were recognised and present in the nursing care home. This presence was valued. Facilitation was routinely provided on a regular basis; it was also available additionally if needed or requested (Table 7.2).

The GSFCH coordinators identified specific activities the external facilitator had helped them with. These related to assisting them during the Implementation Phase

with the coding meetings and linking them with external professionals. The facilitation in the *high facilitation* and *high facilitation and action learning* group was concerned with ‘being present’ and proactively visiting the nursing care homes. However, the emphasis of the external facilitator’s input when they visited was that of empowerment (Table 7.2). There was clear reference to the role modelling aspect of the facilitation they provided. There was also reference to the relationship and partnership working that developed as the external facilitator and the nursing care homes worked together to implement the GSFCH programme (Table 7.2).

The external facilitators recognised that there were external challenges to this approach of ‘being present’ facilitation. These included the cancellation of planned meetings and delivering such an approach, when the role was part time. It was, perhaps, not surprising that one of the external facilitators with extensive experience of working in a care home setting, suggested an alternative definition of facilitation might be needed.

‘And I, (chuckles) I’m thinking, mmm, I’m not sure some of the homes that would think we’ve made it particularly easy, and we may have made their lives a lot more difficult..... obviously facilitate does mean to make easy, but....’.[F6]

However ‘being present’ was reported by an external facilitator as a good approach to facilitation: *‘I definitely think that (pause) no facilitation is not an option, so I, there’s got to be facilitation. I think that, when, when (F1 own manager) first came and we talked about this ‘high’ facilitation, I thought it was a bit overboard, but, so the*

pendulum for me swung right from one end to the other, and now I feel it's kind of settled, but more towards the 'high' facilitation.' [F1]

The Regional Training Centre provided a second form of facilitation of the GSFCH programme. Unlike local facilitation, support and advice from the Regional Training Centre, was available to all facilitation groups, at any time, throughout the two year GSFCH programme. This support is now described.

7.4: Support from the Regional Training Centre

At the start of the GSFCH programme, the GSFCH coordinators and external facilitators of all 38 nursing care homes were given the contact details of the Regional Training Centre. This format of facilitation was similar to the 'as requested' approach, used by some of the *local facilitation* external facilitators.

A prescribed form of support was also provided. GSFCH coordinators and the external facilitators of the *local facilitation* and *no local facilitation* groups were offered the opportunity to phone in and join a teleconference (held every two months for an hour) in the first year. This form of facilitation was provided according to the central GSF protocol. Very few opted to do so. The total time of Regional Training Centre facilitator support requested and given to any nursing care home in the *local facilitation* and *no local facilitation* groups over the entire two year period ranged from none to two hours (Table 7.3).

Table 7.3: Regional Training Centre: advice and support provided to the *local facilitation* and *no local facilitation* participants

Facilitation group	Number of times the GSFCH coordinators and external facilitators contacted the Regional Training Centre				Total
	1	2	3	None	
<i>No local facilitation</i> (n=5)	2	1	0	2	5
<i>Local facilitation</i> (n=9)	2	1	1	5	9
Total	4	2	1	7	14

The GSFCH coordinators and their external facilitators in both high facilitation groups also had access the Regional Training Centre for support and advice (Table 7.4).

Table 7.4: Regional Training Centre: advice and support provided to the *high facilitation* and *high facilitation and action learning* participants

Facilitation group	Number of times face-to-face contact occurred via the Regional Training Centre						Total
	0	1	2	3	4	5	
<i>High facilitation</i> (n=12)	6	3	1	1	0	1	12
<i>High facilitation and action learning</i> (n=12)	5	3	1	1	2	0	12
Total	11	6	2	2	2	1	24

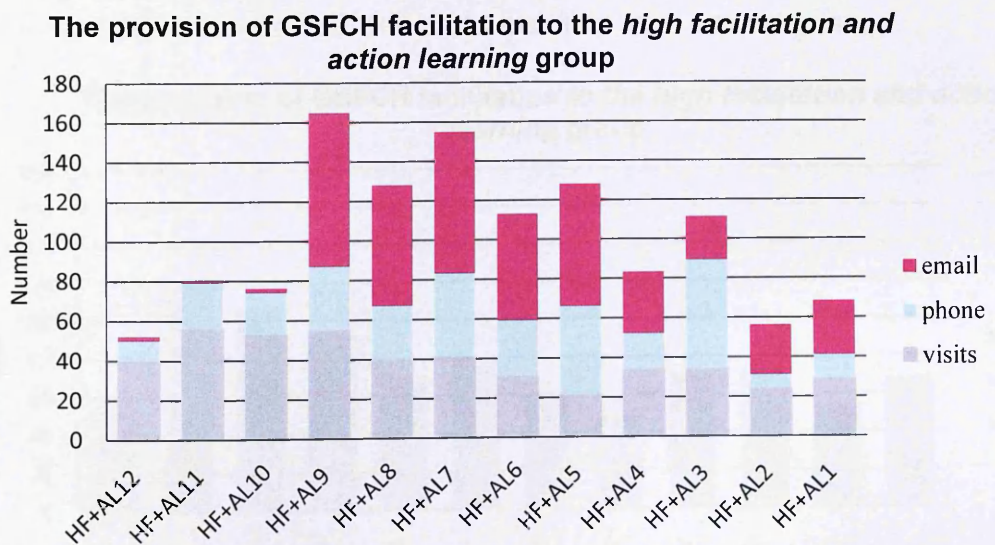
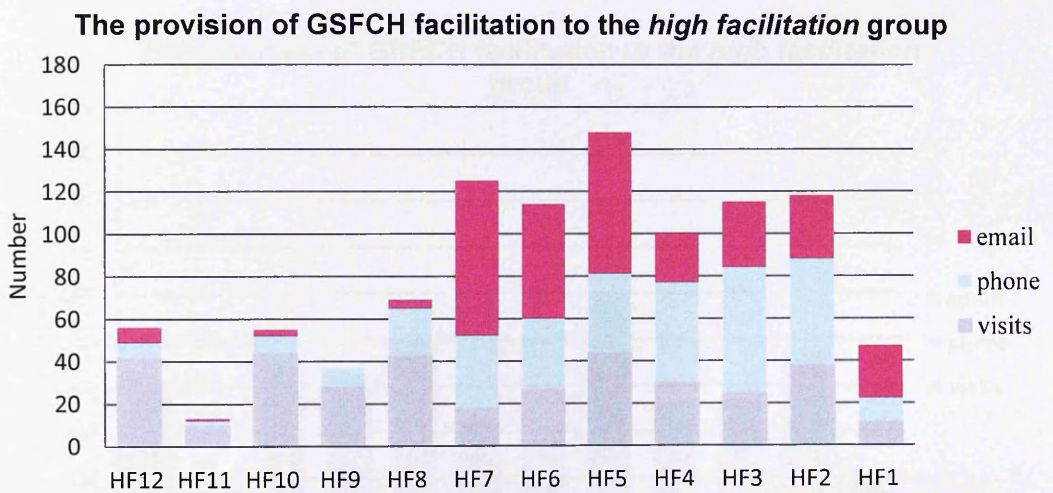
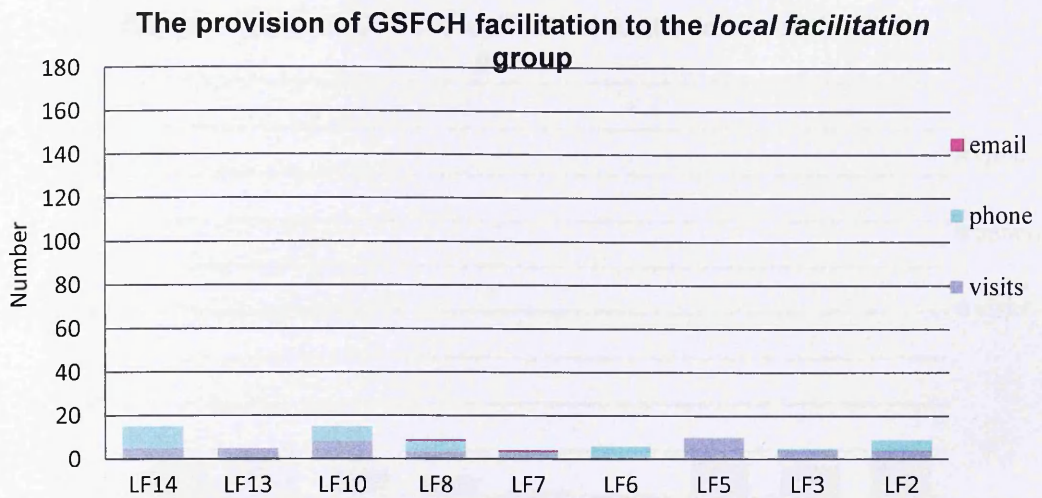
Although only telephone support was offered to the *local facilitation* and *no local facilitation* nursing care homes, the high facilitation nursing care homes (local to the Regional Training Centre) had the option of a face-to-face visit ‘being present facilitation’. Whilst the opportunity to access support from the Regional Training Centre was available to each group, the use of this support was greatest in the *high facilitation* group, with GSFCH coordinators at 13 nursing care homes receiving input. Seven nursing care homes in the *high facilitation and action learning* group sought advice and support and six in the *high facilitation* group. The total time of

support, given by the Regional Training Centre, to the *high facilitation* nursing care homes over the entire two year period ranged from none to 12½ hours.

In addition to the telephone support, GSFCH coordinators from any nursing care home attending the GSFCH workshops without an external facilitator were given half an hour of time by one of the Regional Training Centre external facilitators to develop an action plan on the day. For the *local facilitation* and *high facilitation* groups, this was a form of ‘fitting it in’ facilitation as it had been anticipated their own external facilitator would have attended the workshops to work alongside them.

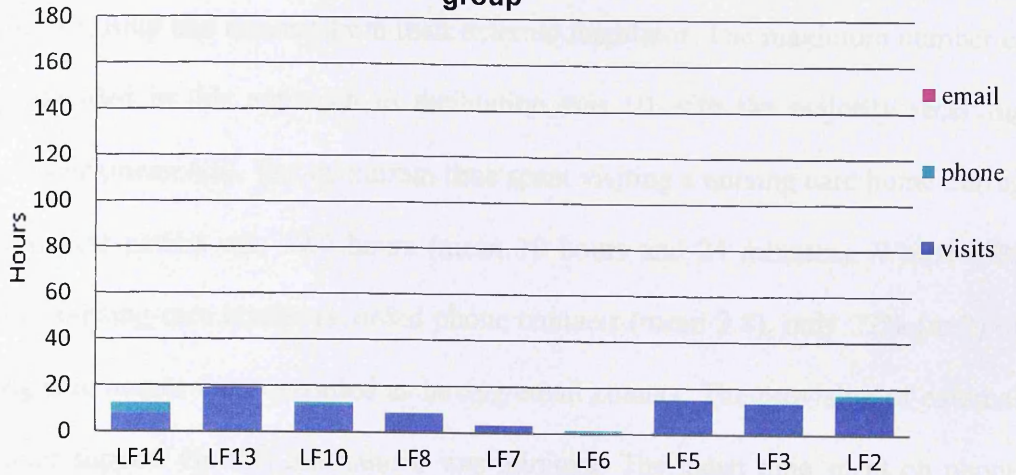
7.5: The recorded delivery of facilitation

There was great variety in the format and duration of the facilitation delivered to the participating nursing care homes. Figures 7.4-7.6 show the difference in the number of emails, phone calls and visits made by the external facilitators across the different facilitation approaches. Figures 7.7-7.9 highlight the differences in time spent. Variety occurred even within the three approaches to facilitation identified.

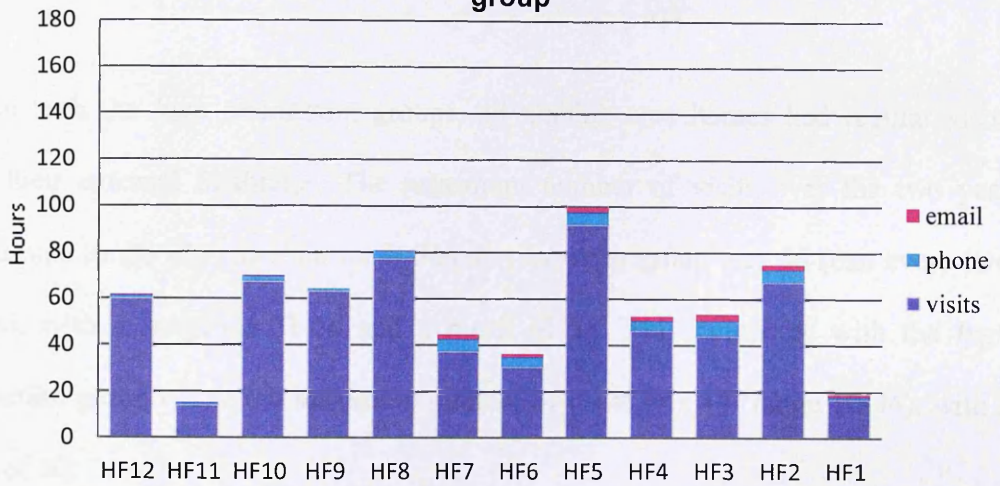


Figures 7.4, 7.5 and 7.6: Number of emails, phone calls and visits by the external facilitator to the nursing care home

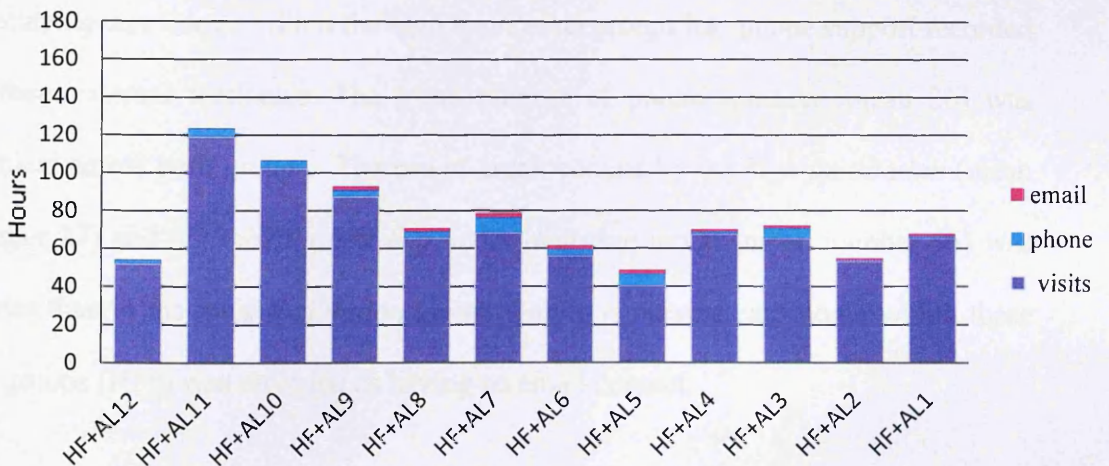
The provision of GSFCH facilitation to the *local facilitation* group



The provision of GSFCH facilitation to the *high facilitation* group



The provision of GSFCH facilitation to the *high facilitation and action learning* group



Figures 7.7, 7.8 and 7.9: Time (hours) of emails, phone calls and visits made by the external facilitator to the nursing care home

Despite having an external facilitator, one nursing care home (LF6) in the *local facilitation* group had no visit from their external facilitator. The maximum number of visits provided in this approach to facilitation was 10 with the majority receiving many fewer (mean 4.6). The maximum time spent visiting a nursing care home during this two year period was 19.0 hours (mean 10 hours and 24 minutes). Whilst 67% (n=6) of nursing care homes recorded phone contacts (mean 3.8), only 22% (n=2) of nursing care homes were recorded as having email contact. The provision of external facilitator support via this mechanism was minimal. The mean time spent on phone contacts was one hour and 10 minutes.

Within both the *high facilitation* groups, all nursing care homes had regular visits from their external facilitator. The maximum number of visits over the two year programme in the *high facilitation and action learning* group was 56 (one every two weeks), with a range of 21-56 and a mean of 38. This compares with the *high facilitation* group where the maximum number of visits was 44 (range 10-44), with a mean of 30.

All nursing care homes within the *high facilitation* groups had phone support recorded by their external facilitator. The mean number of phone contacts (mean 26) was identical across both groups. The use of email contact by the *high facilitation* (mean number 27) and *high facilitation and action learning* group (mean number 36) was greater than in the *local facilitation* group. Only one nursing care home within these two groups (HF9) was recorded as having no email contact.

Across the four groups, the variation in the time of facilitation provided was considerable, ranging from two hours to 224 hours. The *no local facilitation* group received facilitation via the Regional Training Centre. Even where a nursing care home had successfully negotiated the assistance of an external facilitator for one of these nursing care homes, in the *local facilitation* group, the total facilitation time they received was less than six hours. This was only slightly more assistance, over the two year period, than one of the nursing care home in the *no local facilitation* group (Table 7.5).

Table 7.5: Total facilitation time provided to the nursing care home

Facilitation group	Total facilitation time over the entire two year period (hrs/min)	
	Range	Median
<i>No local facilitation</i> (n=5)	2 - 4.30	3
<i>Local facilitation</i> (n=9)	5.55 - 124.27	24.40
<i>High facilitation</i> (n=12)	41.35 - 163.25	120.18
<i>High facilitation and action learning</i> (n=12)	132.25 - 224.08	168.45

The median facilitation time across all groups shows that on average, the *high facilitation and action learning* group received almost 50 hours more facilitation time than the *high facilitation* group. Even if the maximum possible time of action learning is deducted (27 hours), the *high facilitation and action learning* group received the greatest amount of facilitated time to help them implement the GSFCH programme.

7.6: Factors impacting on the Implementation Phase of the GSFCH programme

The four factors identified, by the study participants, that specifically impacted on the Implementation Phase of the GSFCH programme are presented (Figure 7.10). These were:

- internal resources
- putting systems into place
- developing internal relationships within the nursing care home
- building external partnerships

Each of these factors are discussed in turn with emphasis on enablers and barriers of each of these factors and sub-themes.

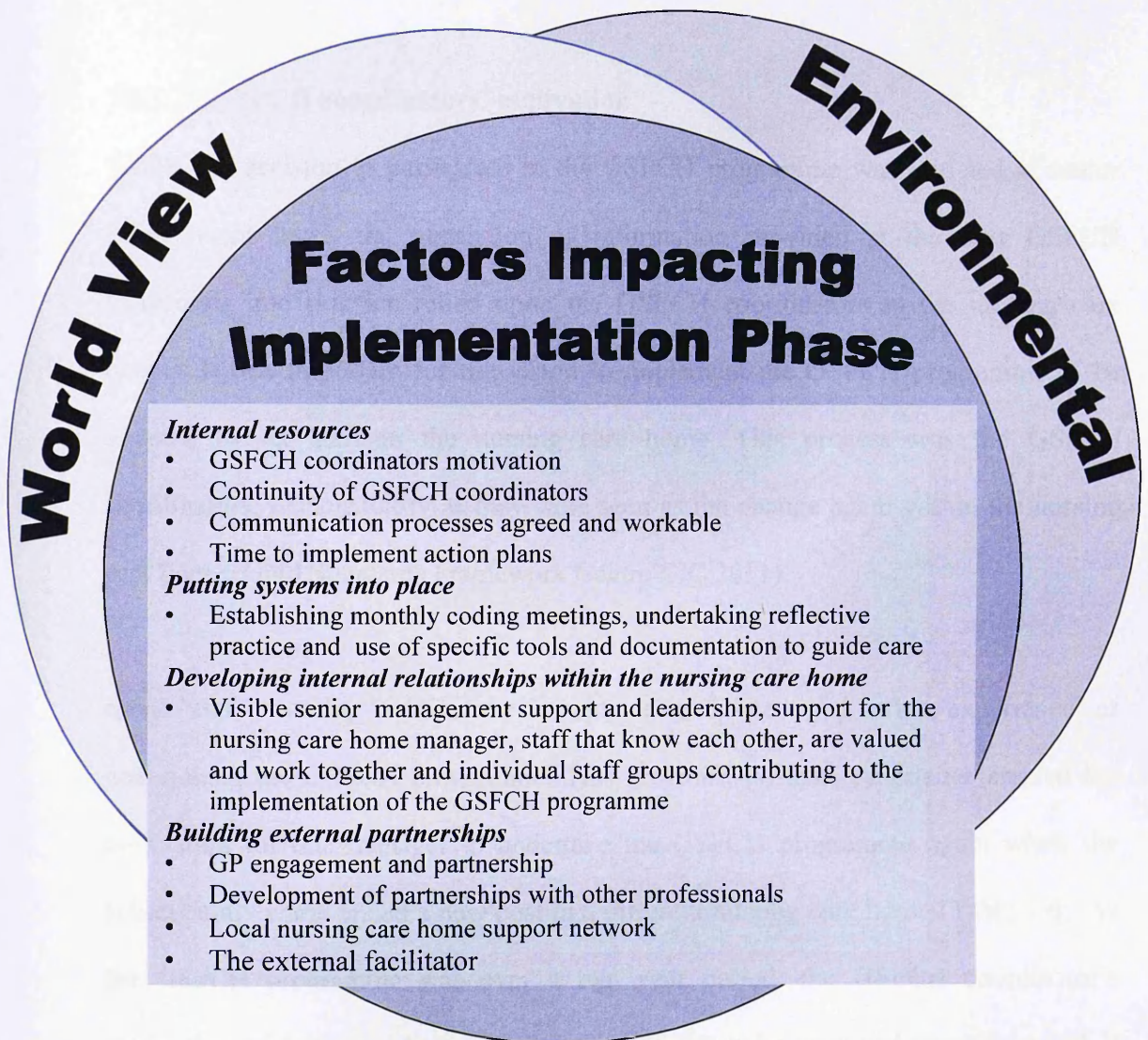


Figure 7.10: Factors impacting on the Implementation Phase of the GSFCH programme

7.6.1: Internal resources

There were four sub-themes identified that related to the level of internal resources in the nursing care home:

- GSFCH coordinators motivation
- Continuity of GSFCH coordinators
- Communication processes agreed and workable
- Time to implement action plans

7.6.1.1: GSFCH coordinators' motivation

Whilst the decision to participate in the GSFCH programme was initiated at senior management level, the translation of information provided at the four GSFCH workshops into practice relied upon the GSFCH coordinators in the nursing care homes. It was important for the vision to implement the GSFCH programme to be adopted by all staff in the nursing care home. This process was the GSFCH coordinators' responsibility as they were seen as the change agent within the nursing care home (Gold Standards Framework Centre CIC 2011).

Some staff working within the nursing care homes had prior experience of undertaking the GSFCH programme. This previous, positive experience created the motivation for one manager to undertake the GSFCH programme again when she subsequently commenced a new post in a different nursing care home (Table 7.6). As the GSFCH programme was over a two year period, the GSFCH coordinator's motivation needed not only to be present, but to also to be sustained throughout and, if the programme was to be sustained, beyond the completion of the programme.

Table 7.6: Internal resources: enablers or barriers to implementing the GSFCH programme

<p>Identified to be important when implementing the GSFCH programme</p>	<p>Act as an enabler if they are in practice during implementation of the GSFCH programme</p>	<p>Act as a barrier to the implementation of the GSFCH programme</p>
<p>GSFCH coordinators motivation</p>	<p>'I am very passionate about the GSF and, having attended the programme in my last post – it was a "must" when I took over my current manager role.' [M.NLF8.000]</p> <p>'This has been a huge learning curve. I have to drive the GSF forward every step of the way. When I have taken my foot off the accelerator it all slowed down.' [C.NLF1.000]</p>	<p>'Well, I think it's been really difficult for them because, erm, they've had changes in staffing and the manager [GSFCH coordinator] who was leading the GSF and has now left, and she was really proactive and great at.' [F17]</p> <p>'Yes, there is another co-ordinator, erm...but I don't know if she's lost interest or her impetus. She does a certain amount and no more, erm, and it is...it's quite a struggle there.' [F2]</p> <p>'They've never really had a consistent second co-ordinator. I think, erm, [A], now, who's a health care assistant, is notionally the second co-ordinator but I can't remember the last time I actually had any contact with her, and she must be the third or fourth sort of second co-ordinator there've been. Other people have come and gone and left.' [F6]</p>
<p>Continuity of GSFCH coordinators</p>	<p>'...To be two of us. We were able to help each other'. [C.HF+AL12.002]</p> <p>'I feel the process is a lot harder than I initially felt. It has been difficult to do by myself as the other coordinator left GSF in November 09...When the second coordinator left the programme in Nov 2009 no one wanted to step up and join myself. The manager said no one wanted to do it and so I had to go alone.' [C.HF3.000]</p>	<p>'Advertising around home – no notice board available.' [C.LF2.001]</p>
<p>Communication processes agreed and workable</p>	<p>'...the majority of homes there'll be very few that'll have access to... computers for learning.' [F10]</p> <p>'...the other co-ordinator doesn't use e-mail very often so you know and I, we're so technology based. If I would turn round and say an e-mail to her would have been great but I can't do that if she's not checking her e-mail.' [F4]</p>	<p>'...although management were saying to them: "You can have as much time as you like to do this." But they're not giving that time.' [F3]</p>
<p>Time to implement action plans</p>	<p>'Thought my enthusiasm would rub off onto other staff, quickly, also allocating 'work' to others with a time to complete – often found staff would say they did not have time-so extra time was built into the working day.' [C.HF7.000]</p>	<p></p>

A number of external facilitators highlighted that the GSFCH coordinators' interest was what was important, not their qualification. They needed to be committed to implementing the GSFCH programme and not give up.

The motivation to drive the programme forward was identified by the GSFCH coordinators as coming from within themselves. The role was identified as hard work, so a key component to this role was their personal belief that implementing the GSFCH programme would make a difference and that the hard work involved was worthwhile. Passion and desire to make it happen was crucial. The GSFCH programme therefore requires someone who cares about its implementation and someone to steer it and to encourage it. Where present this person may have initially been an external facilitator. However, the drive and motivation for its successful implementation into practice needed to be taken up by the GSFCH coordinators and staff within the nursing care home (Table 7.6).

As previously identified the GSFCH coordinator may also be the nursing care home manager. This was the situation in one of the *no local facilitation* nursing care homes. In NLF1 nursing care home, the nursing care home manager/GSFCH coordinator identified that the staff required palliative care training. As she did not have access to an external facilitator she independently implemented this training within her own nursing care home. This was the only nursing care home in the *no local facilitation* group to do this. During my visits, the nursing care home manager/GSFCH coordinator was understandably proud of such an accomplishment. However, what I noted to be of particular importance was, as with everything else, that she had not only shared her vision but also motivated team learning so they could achieve this change

together. In this situation the nursing care home manager/GSFCH coordinator, acted as an internal facilitator.

7.6.1.2: Continuity of GSFCH coordinators

All 38 nursing care homes taking part in the programme initially appointed two GSFCH coordinators. This had resource implications as two members of staff needed time away from clinical practice to attend the GSFCH workshops, and then protected time to implement the programme in the nursing care home. However, when asked what helped to implement the GSFCH programme, the GSFCH coordinators highlighted joint working with each other to be important (Table 7.6).

Over the two year programme, staff turnover meant that the GSFCH coordinators in some nursing care homes changed. A plan of action for this had not always been made and so action to address this, when it did occur, was not always taken (Table 7.6)

7.6.1.3: Communication processes agreed and workable

Both internal and external communication processes were identified as important when implementing the GSFCH programme. However, they varied, not only between nursing care homes but also between individuals within the same nursing care home.

Good communication between the external facilitator, when present and the GSFCH coordinators was important. To achieve this each external facilitator needed to establish not only what communication aids and processes were available, but also what were used by the specific staff, within each nursing care home. The preferred format of communication was not the same for all staff in the nursing care homes. As

one external facilitator explained, even when a specific form of communication, emails, was available, it was important to establish if it was actually being used by that GSFCH coordinator (Table 7.6).

Implementation of the GSFCH programme also required good internal communication within the nursing care home. Some nursing care homes struggled more with this when permission to purchase a notice board was not granted and when access to computers was limited (Table 7.6).

7.6.1.4: Time to implement action plans

At the end of each workshop, external facilitators (their external facilitator if present or the Regional Training Centre facilitators) worked with the GSFCH coordinators to help them produce an action plan. To implement the actions however takes time. Whilst all four different facilitation groups had recognised that time to do this was essential, it was only the staff in the nursing care homes in the *high facilitation* groups that had been given, or had sought, time that was supernumerary highlighting the need for this when implementing the programme (Table 7.6).

One GSFCH coordinator suggested motivation sits alongside time. This suggests time alone may not be sufficient. She emphasised: *'I would just like to mention that honestly for me, two things are highly important to achieve a GOLD STANDARD of care and these are TIME and DEVOTION.'* [C.LF5.001]

7.6.2: Putting systems into place

The GSFCH programme is intended to initiate change. The programme is reliant upon the GSFCH coordinators sharing what they learnt at the GSFCH workshops with all staff in the nursing care home where they work. By doing this the team jointly takes forward its implementation. Three specific actions were required:

- Establishing monthly coding meetings
- Undertaking reflective practice
- Use of specific tools and documentation to guide care

7.6.2.1: Establishing monthly coding meetings

The monthly coding meetings were viewed by the external facilitators as central to the implementation of the GSFCH programme. Such a meeting initiates the action plan for residents' care in the last year of life. Several external facilitators mentioned that if these meetings occurred monthly, even when they did not attend, they believed this meant that cultural change had occurred as the GSFCH programme had begun to become embedded within the nursing care home.

The external facilitators within the *high facilitation* groups invested time in role modelling the coding meetings. They worked alongside the GSFCH coordinators demonstrating how to lead such a meeting. The role modelling of coding meetings occurred in all *high facilitation* nursing care homes that remained open throughout the study. The time devoted to these meetings varied. The external facilitators in the *high facilitation and action learning* group attended the coding meetings in the nursing care home between 3 and 22 occasions and within the *high facilitation* group between 2 and 22 occasions. Coding meetings were attended by the external facilitators in only

33% (n=3) of the nursing care homes receiving *local facilitation*. The time spent role modelling the coding meetings in the *local facilitation* group was much smaller than in the *high facilitation* groups (Figures 7.11-7.13). The importance attached to role modelling a coding meeting was variable across the groups.

No GSFCH coordinator within the *no local facilitation* group mentioned if coding meetings were held in their returned questionnaire; although the nurse managers in two nursing care homes reported coding meetings were held (Figure 7.14). Within the other groups, it was clear that a link had been made between knowledge given at the GSFCH workshop training (the GSFCH coding system) and the clinical practice in the nursing care home. The core 'coding' component of the GSFCH programme had become embraced into the nursing care home culture. The number of nursing care homes holding coding meetings was low in all the nursing care homes at the start of the study (Figure 7.14). The only groups to report that they all held coding meetings 'post' GSFCH programme were the *high facilitation* groups.

Activities undertaken by the external facilitator in the local facilitation group (hours) to put systems into place

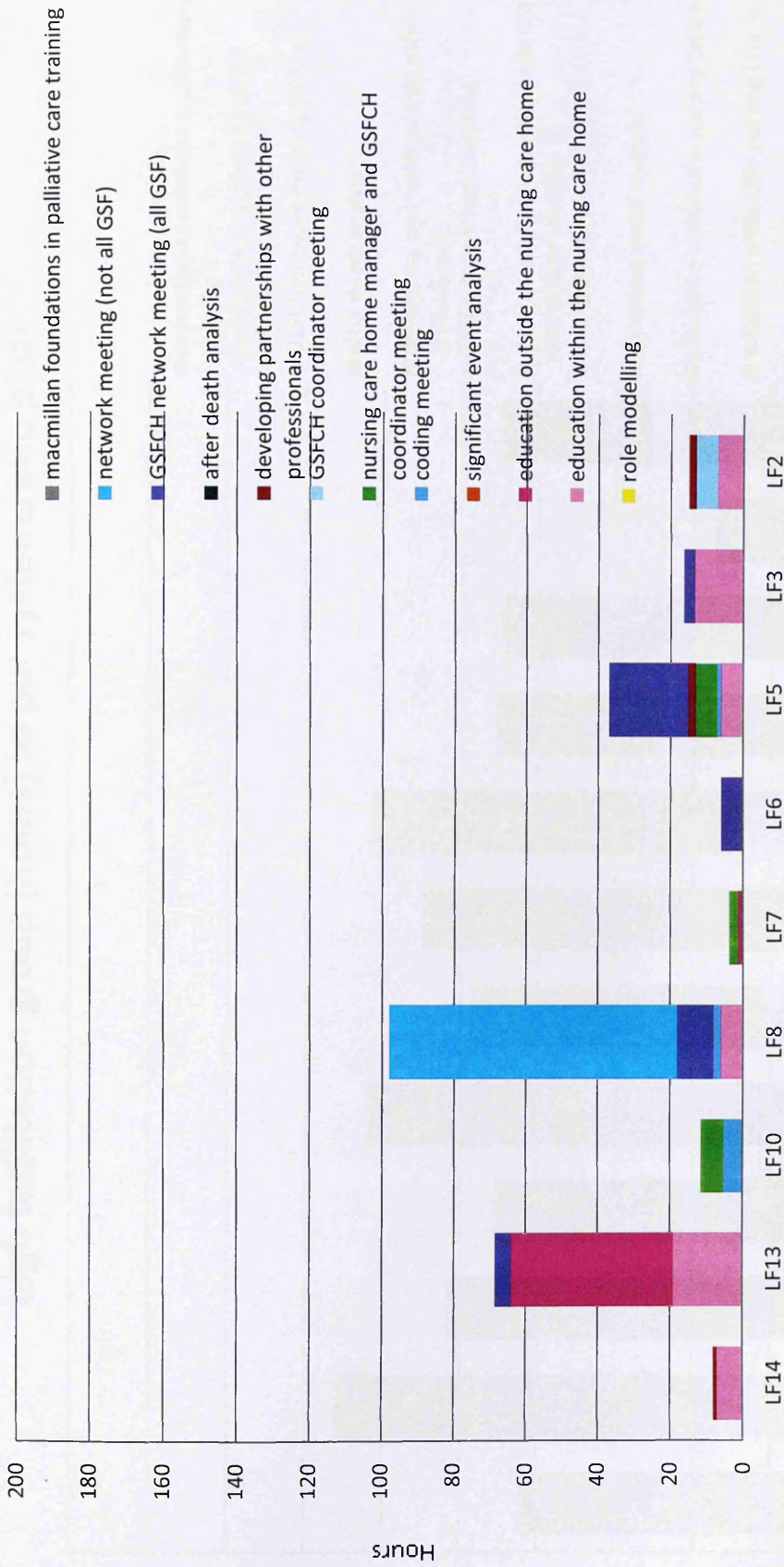


Figure 7.11: Facilitation format provided to the local facilitation group

Activities undertaken by the external facilitator in the high facilitation group (hours) to put systems into place

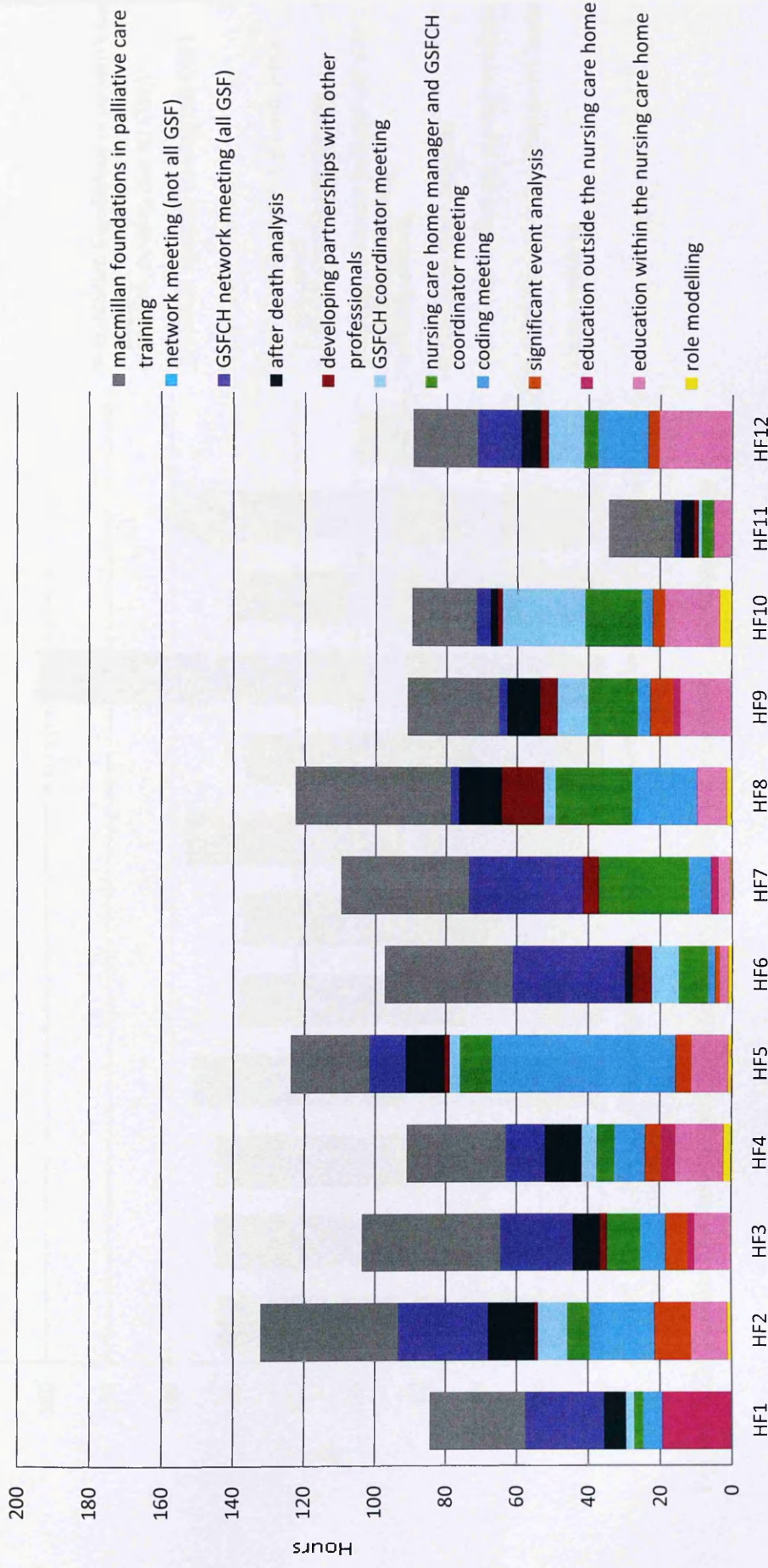


Figure 7.12: Facilitation format provided to the high facilitation group

Activities undertaken by the external facilitator in the high facilitation and action learning group (hours) to put systems into place

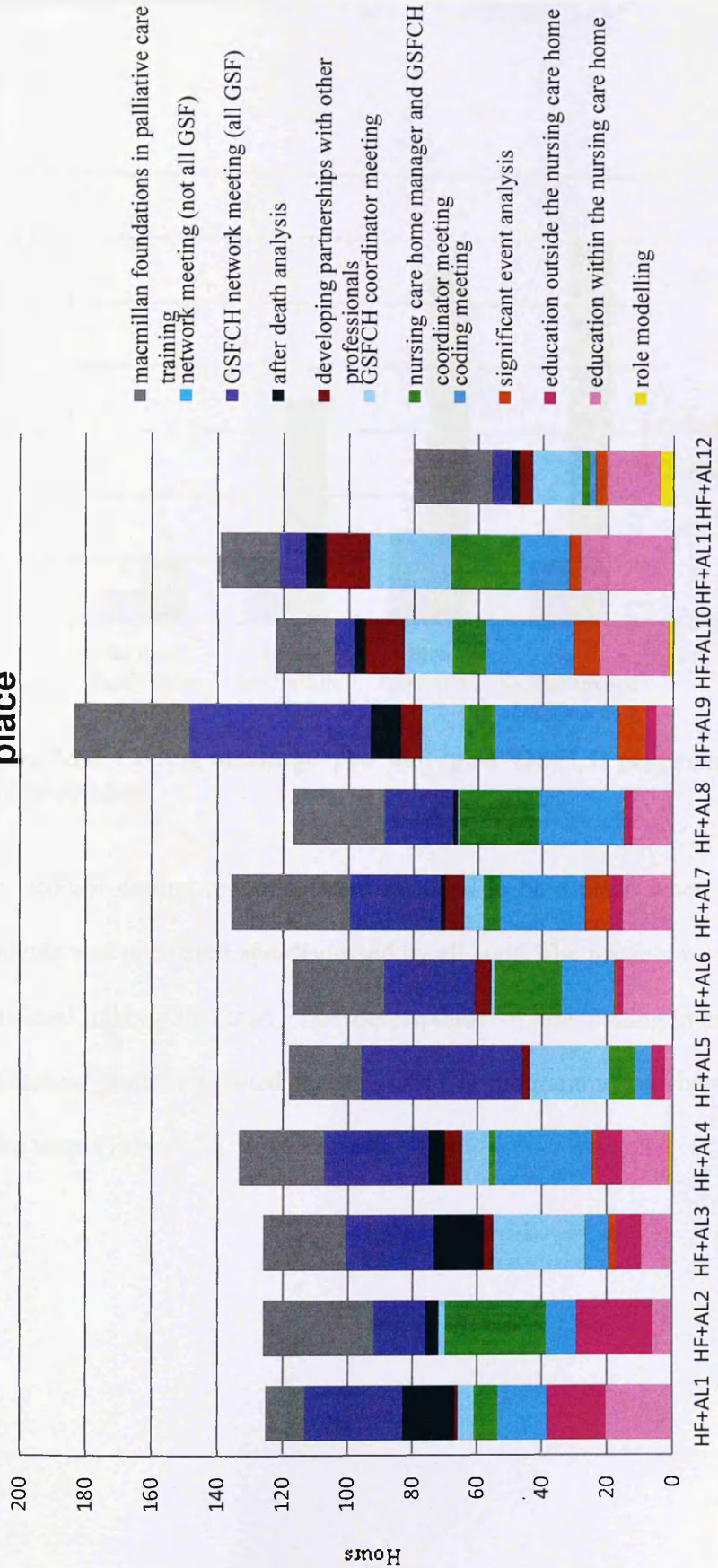


Figure 7.13: Facilitation format provided to the high facilitation and action learning group

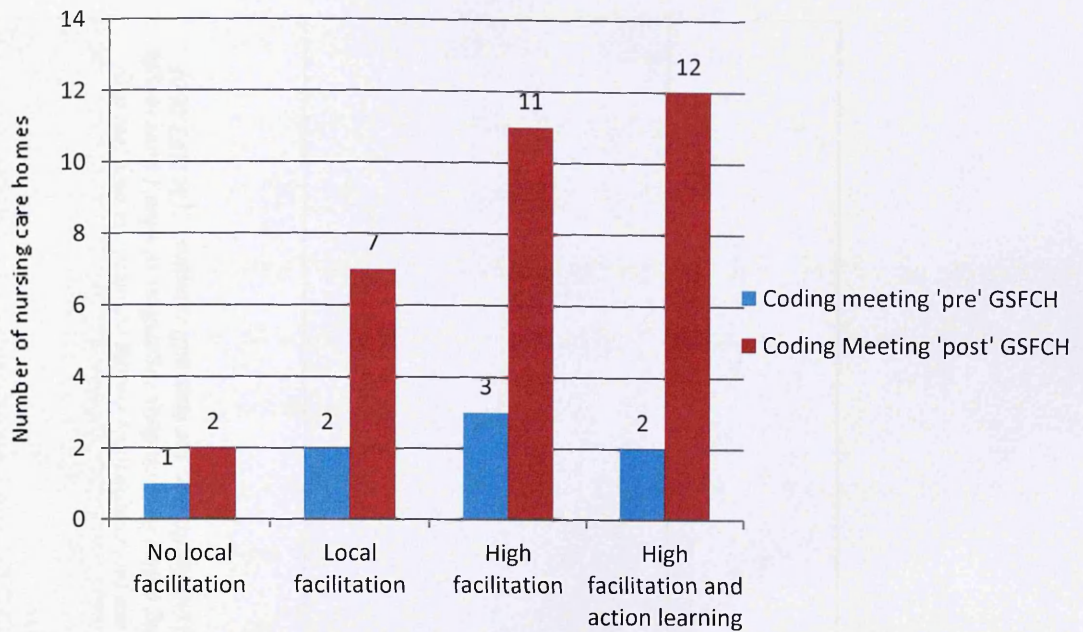


Figure 7.14: Coding meetings ‘pre’ and ‘post’ GSFCH programme implementation

The GSFCH coding meetings were intended to be a place where information about residents was presented and discussed by all staff. The process was not reliant on one individual taking the lead. The descriptions of the coding meetings in the *high facilitation* group suggested that the GSFCH programme had been embraced by the entire team (Table 7.7).

Table 7.7: Putting systems into place: enablers or barriers to implementing the GSFCH programme

Identified to be important when implementing the GSFCH programme	Act as an enabler if they are in practice during implementation of the GSFCH programme	Act as a barrier to the implementation of the GSFCH programme
<i>Establishing monthly coding meetings</i>	<i>'Weekly coding meeting has been a help. Initially it use to be the other coordinator and myself doing all the talking until we got individuals chairing these meetings. Also asking individual staff to present service users health needs got them to read more until the next meeting.'</i> [C.HF4.001]	<i>'Staff do not feel comfortable coding residents as they feel they are putting a time limit on them regardless of what I have taught them and our facilitator, the view still remains...'</i> [M.HF3.000]
<i>Undertaking reflective practice</i>	<i>'It was, because it's just a...you know, they...they just learn from everything that happens and take it forward... They've learned from mistakes; they use reflective practice so well, erm, even when, I mean I did it a few times when there were difficulties quite early on, and they have gone on and used it ever since.'</i> [F2] <i>'a hugely ghastly, discharge... but it also resulted in us having a full meeting with all the nursing homes with the discharge coordinators of the hospital, and we're looking at changing the paperwork that is used between ourselves, just to try and get this a bit better.'</i> [F2]	
<i>Use of specific tools and documentation to guide care</i>	<i>'The structured manner in which the Gold Standard Framework is delivered makes it easier to cover all aspects of care including the correct medication, the assessment tools to ensure that pain, depression and the old constipation are not over looked.'</i> [C.HF+AL8.000]	

7.6.2.2: Undertaking reflective practice

There was evidence of reflective practice (a structured process involving a purposeful discussion that occurs after an experience) occurring within some of the participating nursing care homes. This took a variety of formats:

- Significant event analysis - reflection on an issue that caused concern and the completion of documentation as part of the process and reflective de-briefing occurring after the death of a resident
- After Death Analysis - an audit, within which is a section to complete reflecting upon the death of their resident
- Action learning - for nursing care home managers in the *high facilitation and action learning* facilitation group

Whilst action learning only related to those nursing care homes in the *high facilitation and action learning* facilitation group, significant event analysis and the after death analysis were components of the GSFCH programme. However, where reflective practice had not formed part of prescribed facilitation of the GSFCH programme (i.e. in the *no local facilitation* and *local facilitation* nursing care homes) there was no mention of it occurring in any of the formats listed above.

7.6.2.2.1: Significant Event Analysis (SEA)

Both the *high facilitation* groups made reference to significant event analysis (SEA). Incorporating reflective practice into the implementation of the GSFCH programme was valued by the staff. There was a real sense within both of these groups, that staff were being encouraged to spend time talking together and sharing information. The ability to reflect was highlighted as the mechanism to learn for one nursing care home implementing the programme (Table 7.7).

The external facilitators gave many examples of where undertaking a SEA had moved the nursing care home forward with the GSFCH implementation. The reflection provided both the opportunity to learn from and so to improve subsequent practice and it also provided an opportunity for educational input. Within the *high facilitation and action learning* group, role modelling of SEA occurred in nine of 12 nursing care homes (75%) on between one and seven occasions (median one) which took a total of 45 minutes to 8½ hours (median 3 hours and 35 minutes) in each nursing care home. The external facilitators of eight out of the 12 *high facilitation* nursing care homes (67%) undertook SEA on between one and five occasions (median 3.5), which took a total of 1 hour and 20 minutes to 10¼ hours (median 4 hours and 30 minutes). See Figures 7.11-7.13. Examples were given by the external facilitators of SEA that led to changes within the nursing care home. One example was in relation to hospital discharges (Table 7.7).

7.6.2.2.2: After Death Analysis (ADA)

Completing the documentation for an ADA is a standard component of the GSFCH programme. It is intended that participating nursing care homes undertake this at the start of the GSFCH programme, after the fourth workshop and as they work towards accreditation. It involves reviewing deceased residents' notes and extracting specific details relating to their end-of-life care and completing a section reflecting on the death of the resident. It acts as an audit tool to enable the nursing care home to review the end-of-life care they provided to a specific resident and learn from it. Completion of an ADA was not mentioned by any participant, other than the external facilitator on their activity log. Ten (83%) of the nursing care homes in the *high facilitation and action learning* group and 11 (92%) of the nursing care homes in the *high facilitation*

groups were assisted by their external facilitator to undertake ADA (Figures 7.11-7.13).

7.6.2.2.3: Action Learning

The nursing care home managers in the *high facilitation and action learning* group had access to action learning, a very specific form of reflective practice. In the first year, it was intended that the nursing care home managers from this facilitation group would participate in a three hour action learning set every month, for nine months. Whilst 100% of nursing care home managers attended at least one action learning set, the number attended ranged considerably, from a minimum of one to a maximum of eight sets attended (Table 7.8). Nine nursing care home managers attended six or more action learning sets.

Table 7.8: Nursing care home managers' attendance at action learning sets

Number of action learning sets attended	Total time given of action learning (hours)	Number of nursing care homes (n=12)
1	3	2
2	Not applicable	0
3	Not applicable	0
4	12	1
5	Not applicable	0
6	18	3
7	21	3
8	24	3
9	Not applicable	0

The nursing care home managers attending action learning were each given time to present a difficult situation, in relation to the implementation of the GSFCH programme, that they wanted help to think through. Other members of the action learning set provided high challenge (questioning) and high support (Hockley et al

2013). The experience of attending action learning had clearly been discussed within these nursing care homes. Through completing the questionnaire it became clear that the nursing care home managers, who had come into post after action learning was completed, knew that the previous nursing care home manager had attended these groups. Action learning was valued. The nursing care homes managers recalled their experience positively and were able to articulate the reasons for their view. A major benefit reported by the nursing care home managers from taking part was the opportunity it gave for sharing. The action learning had been instrumental in the GSFCH programme actually being implemented within one nursing care home (see Box 7.1). The nursing care home managers had embraced the principles of action learning. In doing so, they had benefitted from the process individually and collectively.

Box 7.1: Action learning as a mechanism of change

'Enabled creativity and a 'can do' culture in finding solutions to challenges.' [M.HF+AL11. 000]

'With the general feedback from the other managers at the session I was able to realise that some of the issues at my home were similar to other homes. So together we were able to solve some of them.' [M.HF+AL12. 000]

'Action learning sets have encouraged us to be more pro active in challenging and problem solving. This has had a positive benefit, particularly in the level of support received from the GP which is excellent.' [M.HF+AL5. 000]

'Gives confidence in dealing with issues and concerns. Allows a critical thinking approach.' [M.HF+AL9.053]

'Group discussion opens a wider scope of thinking and outcomes.' [M.HF+AL9.053]

'At some point when I felt we could not continue with the implementing the GSF, I had help from my Action Learning group on how to overcome what to me were massive problems.' [M.HF+AL2. 000]

7.6.2.3: Use of specific tools and documentation to guide care

The GSFCH programme encouraged the nursing care homes to use a number of end-of-life care tools and supportive documentation. These include advance care plans, resuscitation decisions, symptom assessment tools, and an end-of-life care pathway. The use of the tools that the GSFCH programme provided enabled the programme to be implemented. For example, their use guided the care of residents and enhanced staff communication: *'It was always a difficult issue to talk about end-of-life care. But now with ACP, LCP.....'* [C.HF+AL12.002]

The GSFCH coordinators within the *no local facilitation* nursing care homes, were the only group that made no reference to the use of any documentation or end-of-life care tools. The other three facilitation groups reported the documentation and assessment tools that the provided as part of the GSFCH programme were both used and valued (Table 7.7).

Once implemented, the documentation and tools included in the GSFCH programme structure guided staff in their care of residents in the last year of life. Whilst putting this structure into place was noted to take time, it was interesting that only the GSFCH coordinators in both *high facilitation* groups secured additional supernumerary time to do this. Once the tools were in place and being used, the staff felt they saved time. This suggests that whilst additional time was needed to initially put the system into place, long-term, its implementation saved time.

'Now, with the advance care plan in place, coding meetings, and the LCP, I found communication to be much better. We don't seem to be working under pressure at all.' [C.HF+AL6.000]

7.6.3: Developing internal relationships within the nursing care home

The GSFCH programme enables the care nursing care home to develop and deliver high quality palliative care for all of their residents, but to do so staff needed to work together. Four themes were identified that related to developing relationships within the nursing care home:

- Visible senior management support and leadership
- Support for the nursing care home manager
- Staff that know each other, are valued and work together
- Individual staff groups contributing to the implementation of the GSFCH programme.

7.6.3.1: Visible senior management support and leadership

The GSFCH coordinators within the *no local facilitation* group made no mention of management support. Participants from every *local facilitation* and *high facilitation* recognised that management support enabled implementation of the programme. Whilst motivation to initiate and implement the GSFCH programme into practice was essential (Table 7.6), there seemed to be recognition that this needed to be present at management level. High motivation and enthusiasm demonstrated by the nursing care home manager encouraged acceptance of the changes that needed to occur, for the GSFCH to be implemented (Table 7.9).

Table 7.9: Developing internal relationships: enablers or barriers to implementing the GSFCH programme

Identified to be important when implementing the GSFCH programme	Act as an <u>enabler</u> if they are in practice during implementation of the GSFCH programme	Act as a <u>barrier</u> to the implementation of the GSFCH programme
Developing internal relationships within the nursing care home	<p>'The manager was a keen leader and the rest of the team welcome the challenge for the benefit of people under our care.' [C.HF+AL6.001]</p> <p>'... they all work very well as a team all levels of the home. There's... it's not very hierarchical in the way that it works: it's very informal, erm, and quite friendly in its approach. I think that makes it a really good learning environment actually, because... there's a like, erm... I call it, erm, a joyful buzz, you know... there's lots of things going on but not in a stressful way...' [F13]</p>	<p>'If I haven't got a manager's support or I haven't got a manager that is not pushing it, at a managers level, and not making sure these things happen and not giving staff time to attend study days or to have coding meetings it tends to be much more of a struggle for that home to be to be part of the programme.' [F3]</p>
Support for the nursing care home manager	<p>'The company to support HF12 staff.' [C.HF12.000]</p> <p>'... not the Manager, the home owner.... very proactive and knows about Gold Standards, and I think is very supportive because of that. It's not part of a group therefore money is very tight, but actually she, she gives more in time and understanding than I think any other owners, which is hugely beneficial.' [F2]</p>	<p>'... They (care home provider) seem to sort of move their managers, to troubleshoot in a residential home for a week and then come back. So they've never quite got the, the support, they've never quite given the time to make things happen in the care home. And I know this last manager... she just got really frustrated with it and just felt that they were just not giving her the level of support they had actually promised and she left unfortunately.' [F3]</p>
Staff that know each other, are valued and work together	<p>'It has made me realise that work is easier when everybody in the home is involved.' [C.LF13.000]</p> <p>'... until we started doing GSF... the opinions of Health Care Assistants wouldn't have ever been taken particularly seriously. Whereas now, there's a real move for listening to what the Health Care Assistants say, and, and activity co-ordinators and things, not to just dismiss them.' [F16]</p>	<p>'Most staff leaving and having to start all again inducting new staff.' [HF4.001]</p>
Individual staff groups contributing to the implementation of the GSFCH programme	<p>'We had no resistance to GSF from any of the staff, care staff especially have a great interest in end-of-life care, often chose this subject to discuss or wish for more training.' [C.LF2.000]</p> <p>'... we got the night staff in because we felt that they had been missed out... that a lot of them weren't actually sure what was going on, and weren't very enthusiastic. And in fact they came in... they were excellent... I don't think they'd been included. They were more enthusiastic than the team leaders, which was interesting.' [F8]</p>	<p>'In nursing homes, RGNs do not think outside the box and do not like change.' [C.HF7.028]</p> <p>'Getting night staff involved.' [M.HF+AL2.000]</p> <p>'Convincing carers that they are a valuable part of the process... Convincing ancillary staff e.g. housekeepers that they are important' [C.LF14.001]</p>

The nursing care home manager works across the entire nursing care home and this offers the potential to influence practice, by sharing good practice between sub-units which may have subcultures (see 3.1). Sub-units varied between nursing care homes but included different floors, separate units caring for different client groups and different groups of staff members within the nursing care homes. The sharing of information in this way may be especially important where no external facilitator is present.

The time the external facilitators spent in meetings with the GSFCH coordinators, where the nursing care home manager was also present, in the *local facilitation* group, was minimal. In the entire two year period, this only occurred within three (33%) of the nine *local facilitation* nursing care homes group (see Figures 7.10-7.11). The mean time spent doing this was one hour and 41 minutes (range 2 hours and 45 minutes to 6½ hours). This contrasts to the *high facilitation* groups where 100% of the external facilitators recorded spending time with the nursing care home manager. In the *high facilitation and action learning* group, the mean time spent doing this was 12 hours and eight minutes (range 2 to 31½ hours) whilst in the *high facilitation* group, the mean was lower at 10 hours and 29 minutes (range 4 to 25¼ hours).

There was recognition by the GSFCH coordinators and the external facilitators that the support of the nursing care home manager was essential for change to occur. The nursing care home manager therefore needed an understanding of what the GSFCH coordinators attending the GSFCH workshops were required to achieve. The process was reported to be much easier, when the nursing care home manager knew about the GSFCH programme (Table 7.9). For example, the nursing care home manager's

presence at GSFCH meetings meant they led by example. Their presence enabled and encouraged staff to attend. A number of external facilitators recognised that leadership was an important quality of the nursing care home manager (Table 7.9). The nursing care home manager had the power to enable change to occur. Engagement at management level ensured not only that decisions occurred, but that the decisions actually changed practice.

7.6.3.2: Support for the nursing care home manager

Whilst the nursing care home managers did not mention the need for support by the nursing care home owners, both groups of *high facilitation* GSFCH coordinators and external facilitators did. Perhaps they saw that the support for the implementation of the GSFCH programme was only possible, if there was commitment across all levels within the nursing care home. This included the team above the nursing care home manager (Table 7.9).

7.6.3.3: Staff that know each other, are valued and work together

The focus in the *no local facilitation* group was on the individual GSFCH coordinator's personal training and learning. However one GSFCH coordinator, (was also the nursing care home manager) recognised the need for the entire nursing care home to adopt the principles of the GSFCH programme. She saw the importance of providing face-to-face education sessions for all staff members. She believed it was important to know the staff thoughts, and to be able to address any concerns they had about end-of-life care. This involved spending time with them and them spending time with each other. She used the opportunity to increase understanding between herself and her team and between her team members, which would not have occurred if she

had organised independent study. It was her joint management position and GSFCH coordinator role that enabled this process to occur. Her passion and drive empowered her to run internal education sessions and motivate all her staff:

'She and three members of her staff have taught all the other staff the Macmillan 'Foundations in Palliative Care'. She learnt loads about her staff doing this e.g. multicultural beliefs re death and dying as she has totally multicultural workforce. We had a really interesting discussion about how this really helped her develop a relationship with the staff. The cook and domestics loved the sessions they now see their place in the GSFCH programme and the provision of end-of-life care. She hosts as many events as she can in the home for the community matron e.g. verification of death. That way her staff go for free.' (Researcher)

Other than this one example, there was no mention within the *no local facilitation* group of teamwork. There was no sense either of the structure of the GSFCH being adopted and implemented by the entire nursing care home team. By contrast, the *high facilitation* groups both stressed that implementation of the programme would only occur if adoption of the programme occurred by every staff member. This had involved significant change within some of the nursing care homes (Table 7.9).

The *local facilitation* nursing care homes were the only group to acknowledge that they had been fortunate to have a stable staff workforce and they believed this had enabled the programmes implementation. The staff in the nursing care home knew each other and all knew about the GSFCH programme from the outset. This collective knowledge and shared experience amongst the staff was interpreted by the external

facilitators as implying they were able to work together to implement the GSFCH programme. There was no interruption by new members to the team, who might have had different views or knowledge of the programme.

The external facilitators provided examples of the strong link between teamwork and leadership. One nursing care home manager really learnt how to lead, not just manage her team:

'But I support them. We have meetings....And then she suddenly I think had talked it through on some action learning and realised actually what it was she was doing very much manage at top, managing from the top... and now she realises that she gets much more out of her staff by listening to what they are saying.' [F3]

7.6.3.4: Individual staff groups contributing to the implementation of the GSFCH programme

The *high facilitation and action learning* group were the only group that did not suggest that embracement of the GSFCH programme by different staff groups had aided its implementation. This factor was however recognised by the GSFCH coordinators within all other facilitation groups. They and the external facilitators, where present, recognised the role of non-nursing staff in the GSFCH implementation (Table 7.9).

The GSFCH programme could only be implemented with the engagement of all staff. The GSFCH programme offered the non-nursing staff the opportunity to contribute to decisions and to share information. Care provision within the nursing care home culture can be hierarchical where non-nursing staff previously would have been

expected to only provide hands-on-care. This change was one they welcomed and embraced. Implementation of the programme was encouraged as peers listened to peers.

With respect to implementation, the external facilitators in the *local facilitation* group reported that it was important to have everyone in the nursing care home involved, in order for the GSFCH programme to be fully implemented. They recognised that this did not just mean RGNs and care assistants and there were examples given of teaching sessions encompassing catering staff and handymen. The night staff's engagement was also viewed as crucial and several external facilitators targeted specific training for them. This involved the external facilitators working in the evening and the night shift coming in early. A number of external facilitators felt this was essential and set time aside to meet them (Table 7.9)

7.6.4: Building external partnerships

The GSFCH programme actively promoted collaboration/networking between the nursing care home and external practitioners and organisations. This was one of the three main aims of implementing the programme and so this should have occurred and emerged. The GSFCH programme could not be successfully implemented without such outside collaboration. Building external partnerships was reported to have occurred in relation to:

- GP engagement and partnership
- Development of partnerships with other professionals
- Local nursing care home support network
- The external facilitator

7.6.4.1: GP engagement and partnership

The monthly GSFCH coding meetings could not occur without collaborative work with the GP. GPs were needed to help with specific medical activities such as signing resuscitation decisions and prescribing end-of-life care medication.

In the *no local facilitation* nursing care homes, links with their external community did not occur. This insular pattern of working included working with their GP. When reference was made to the GP, by the GSFCH coordinators, it was in relation to getting them to assist, rather than partnership working: *'Getting GP to complete out of hours form.'* [C.NLF11.000] This contrasts with the other three facilitation groups, where the links with outside agencies were highlighted to be important, when implementing the GSFCH programme. Establishing links and working alongside the GP was seen to be important (Table 7.10).

The external facilitator enabled staff in the nursing care home to be creative, when establishing relationships with GPs, and getting medical support. One external facilitator mentioned the need for the GPs to see their nursing care homes contribution was useful to the work the latter already had to do:

'He has a lot of paperwork to do which I hadn't realised from his point of view when somebody dies from the register he's got a lot of paperwork to fill in. So, in fact the care home doing Gold Standards Framework halve that paperwork, most of that paperwork is already done because they, he can tick automatically that they're on a register...they've got a, err, an advanced care plan and...a signed DNAR. So in a way the care home are helping him with their end-of-life residents, with his register as well.' [F3]

Table 7.10: Building external partnerships: enablers or barriers to implementing the GSFCH programme

Identified to be important when implementing the GSFCH programme	Act as an <u>enabler</u> if they are in practice during implementation of the GSFCH programme	Act as a <u>barrier</u> to the implementation of the GSFCH programme
GP engagement and partnership	'Fortunately we have a very supportive GP who from the admission of a resident until their death is happy to get involved with the relatives by informing and supporting.' [C.LF14.001]	'I think the GPs have been difficult. I find the two major GPs out there quite challenging erm because that have, they're, I don't know if it's a cultural thing - they are both Asian GPs - and whether they find it difficult with end-of-life care.' [F3]
Development of partnerships with other professionals	'No facilitator from outside but we work together with the palliative team who are giving a lot of training and do workshops in our home.' [M.NLF4.074] 'CNS from Palliative Care Team will come to give support and advice when we refer to them and come to present GSF meeting once a month.' [C.HF 12.001]	'To arrange GPs and other specialist to attend coding meeting is not an easy task.' [C.HF+AL4.002] 'Lack of good communication between hospital and care home.' [C.HF+AL4.092]
Local nursing care home support network	'Training that has been put on by GSF programme, with the added benefit of meeting staff from other homes. It is interesting to hear and share ideas and challenging situations.' [C.HF+AL8.000]	'You know, that's the only other thing I can offer them now. They're part of the cluster group and I think they'll send people on the cluster group training because they're, they're hosting it. Err, they don't send anybody on their meetings now, you know, the, the three monthly co-ordinators meetings.' [F3]
The external facilitator-valuing and attending the workshops with the GSFCH coordinators	'Meeting nurses from other homes, sharing their concerns and experiences.' [M.HF5.063] 'I thought... You know, I think it'd be a good idea if I actually attended the workshops and (chuckling) understood what they did...so that, erm, I could understand what went on in the workshops.' [F13] '... although I'd gone over the essence of it, erm, and explained to you know, a long time before, erm, Phase 6 (the GSFCH programme) started about what was needed and the elements of the workshop. I don't think there's anything quite like coming onto the workshops, for it really to make sense.' [F6]	'Erm...I think I missed a couple of the days up at [Hospice] and...the first two that I went to had actual action plans, and, you know, I actually came back to them... so we did both of them actually - but I wonder ... what to do next and...' [F11] 'I think difficulties have been change in management, change in team leaders and co-ordinators, so we've now got two new co-ordinators that didn't go on the initial programme or workshops.' [F9]
The external facilitator-investing time to establish a relationship with the nursing care home	'...what we did before they started the GSF programme, we, erm, we ran quite an intensive, erm, Foundation in Palliative Care Course for them... so that kind of, in a way...enabled us to get to know the teams...I think that's probably why they then, erm, went on to see whether we would support them through the GSF programme.' [F7]	'Yes, sure. I mean I'm going to, erm, I've emailed them to say that I'm free on Tuesday next week...so I'm hoping that I'll be able to go in then...just waiting for them to...cos I haven't had time to ring them so...' [F17]
The external facilitator-'being present' in the nursing care home	'if you did it over the telephone, or something like that, it just wouldn't be, wouldn't be the same. Things come up, discussions aren't the same. You can pick up from body language of the staff if you actually see them and er interact with them about how comfortable they are with you'. [F15]	'They would have, they were invited, everybody gets an email.' [F17] 'If I didn't go in, erm, you know, sometimes the meeting didn't happen.' [F5]

The external facilitators saw that GPs were crucial to the implementation of the GSFCH programme. They saw that their role was as supporting the GP, as well as the staff in the nursing care home. The external facilitator promoted the nursing care home relationship with the GP. A relationship may have been pre-existing, but the external facilitator helped develop this. However, this became more challenging where nursing care homes had more than one GP attached to them.

The number of GP practices supporting the nursing care homes in each facilitation group varied. Half of both high *facilitation* groups were supported by one GP practice. This may have aided relationship building between themselves and the GP. Only a third of the *local facilitation* group had support by one GP and a fifth of the *no local facilitation* group (Table 7.11). Nursing care homes across all groups had as many as four to six GP practices supporting them.

Table 7.11: GP practices with residents in the nursing care home

Nursing care home divided by facilitation groups	The number of GP practices with residents in the nursing care home						Total
	1	2	3	4	5	6	
<i>No local facilitation</i> (n=5)	1	1	1	2	0	0	5
<i>Local facilitation</i> (n=9)	3	1	3	0	0	2	9
<i>High facilitation</i> (n=12)	6	3	1	0	1	1	12
<i>High facilitation and action learning</i> (n=12)	6	3	1	1	1	0	12
Total	16	8	6	3	2	3	38

7.6.4.2: Development of partnerships with other professionals

The development of partnerships with external professionals was perceived by the GSFCH coordinators and the external facilitators of the *no local facilitation*, *local facilitation* and *high facilitation* groups, as aiding the implementation of the GSFCH

programme. Within the *local facilitation* group, 33% (n=3) were assisted by their external facilitator to establish and develop partnerships with individuals external to the nursing care home (Figure 7.10). The mean time spent doing this was 33 minutes (range 1 to 2 hours). The nursing care homes in the *local facilitation* group were empowered to form partnerships with their local palliative care service, clergy and the undertakers. These relationships were new to the respective nursing care homes and initiated as a consequence of implementing the GSFCH programme.

In the *high facilitation and action learning* group the mean time spent doing this was four hours and 47 minutes (range 0 to 13¾ hour) whilst in the *high facilitation* group, the mean was lower three hours and eight minutes (range from 0 to 5 hours and 35 minutes). Time was spent by the external facilitator with the high facilitation group forming multiple partnerships which included the GP, the out-of-hours manager, the local hospital discharge coordinators, the local palliative care service, the care home support team, relatives, a local arts project and the practice manager. A similar diverse pattern occurred within the *high facilitation and action learning* nursing care homes. Here, additional partnerships included social workers, the dementia CNS, district nurses and a psychiatrist.

The focus of implementing the GSFCH programme within the *no local facilitation* nursing care homes was on education and lectures. Their link with the palliative care team was therefore in relation to this form of support. One of the external facilitators gave an example of a GSFCH coordinator linking with the hospice in this way, when she was unable to provide the training they needed (Table 7.10).

The *local facilitation* external facilitators mentioned networking with other professionals, to link them with the nursing care home. One example was with the CNS in palliative care. The *local facilitation* group indicated that they were mainly using them as a resource for residents who had cancer. Very few nursing care home residents fall into this category. This would have limited their use of this service. In contrast, the *high facilitation* group had fully integrated with the palliative care team. They visited monthly and had become engaged with the GSFCH implementation (Table 7.10).

Whilst the external facilitator described engaging the *high facilitation and action learning* group with external professionals, such as the district nurses and SPC, the nursing care home managers and GSFCH coordinators of this group reported no links with outside agencies, when they described what assisted them with implementation of the GSFCH programme. The *high facilitation and action learning* group instead, perceived that the linkages between themselves and other nursing care homes contributed to implementation the GSFCH programme (Table 7.10). The external facilitators had been instrumental in this process.

7.6.4.3: Local nursing care home support network

No mention was made by any of the GSFCH coordinator within the *no local facilitation* nursing care homes of making contact with, or forging supportive links with, other local nursing care homes. This was in spite of the fact that local GSFCH coordinator meetings, occurring between each of the four workshops should have been a core component of the GSFCH programme (see 2.6.1). There was comment, in the *local facilitation* group, that such links would be useful, however no nursing care

home had taken the initiative to forge such a relationship: *'It would have been useful for the GSF to arrange buddy system with another home, who you knew was willing to give advice.'* [M.NLF9.000]

The value of forging links with local nursing care homes, when implementing the GSFCH programme, was highlighted by the *local facilitation* and both the *high facilitation* groups. There is a view that as nursing care homes are independent businesses, such linkage between nursing care homes, may not be possible, or desired. However what was reported was the value of these links (Table 7.10).

What also seemed important was the development of these meetings, their regularity and their location. One of the external facilitators commented that she believed these meetings worked well because they were commenced in the Preliminary Phase, at the beginning of the programme, so all the nursing care homes were at the same level. There was no competition between them and they had an opportunity to build up a relationship between workshops. The meetings were held between the GSFCH workshops and within other nursing care homes: *'Cluster group meeting at different home'* [C.HF+AL4.002]. This perhaps encouraged the nursing care homes to take ownership of the meetings.

Encouraging and enabling nursing care homes to network together, to share and learn from one another, was central to the facilitation provided in both the *high facilitation* groups. There was evidence of this occurring with one *local facilitation* external facilitator, who had been in post for a number of years. Her prior experience had taught her that this helped with the implementation of the GSFCH programme.

In the *high facilitation and action learning* nursing care homes, some nursing care home managers took on a facilitation role themselves: *'I've found the Manager's been very, very supportive with other homes and keeping the impetus going for them as well, that they've got another port of call to phone.'* [F2] Several external facilitators commented that they did not believe the nursing care homes would have started to network with one another, if they had not initiated and then helped to support them.

A local care home support network was also developed through two specific activities of both the *high facilitation* group external facilitators. Both of these groups offered the GSFCH coordinators the Macmillan 'Foundations in Palliative Care for Care Homes' training, prior to the first workshop. The nursing care home managers in the *high facilitation and action learning* group also had access to action learning. Unlike the Macmillan 'Foundations in Palliative Care for Care Homes', this training established a supportive care nursing home network at management level.

7.6.4.4: The external facilitator

The external facilitator was described as enabling the implementation of the GSFCH programme by:

- Attending the workshops with the GSFCH coordinators
- The external facilitator investing time to establish a relationship with the nursing care home
- 'Being present' in the nursing care home

7.6.4.4.1: Attending the workshops with the GSFCH coordinators

The external facilitators were encouraged to attend the GSFCH workshops that were held at the Regional Training Centre, to work alongside the GSFCH coordinators. Whilst the external facilitators of both the *high facilitation* groups attended all the workshops, this was not the case in the *local facilitation* group. Within this group, only one external facilitator attended all four workshops. Six of the nine *local facilitation* nursing care homes had their external facilitator attend the GSFCH workshops, with their GSFCH coordinators, on a maximum of one occasion (Table 7.12).

Table 7.12: External facilitators' attendance at the GSFCH workshops

Facilitation group	Number of GSFCH workshops where the external facilitator attended to work alongside the GSFCH coordinators (n=33)				
	0	1	2	3	4
<i>No local facilitation</i> (n=5)					
<i>Local facilitation</i> (n=9)	2	4	2		1
<i>High facilitation</i> (n=12)					12
<i>High facilitation and action learning</i> (n=12)					12
Total	2 (6%)	4 (12%)	2 (6%)	0	25 (76%)

During the first year of the GSFCH programme, the GSFCH coordinators should attend four workshops (Gold Standards Framework Centre CIC 2011). In total, n= 27 (71%) of the participating nursing care homes had a GSFCH coordinator attend all four GSFCH workshops. Distinct differences within the facilitation groups occurred (Table 7.13). Whilst at least one GSFCH coordinator from the *high facilitation and action learning* and *no local facilitation* groups attended all four GSFCH workshops, this was not the case within the other facilitation groups.

Table 7.13: GSFCH coordinators' attendance at the GSFCH workshops

Facilitation group	Number of GSFCH workshops that any GSFCH coordinators attended (n=38)			
	1	2	3	4
<i>No local facilitation</i> (n=5)				5
<i>Local facilitation</i> (n=9)			4	5
<i>High facilitation</i> (n=12)	1	4	2	5
<i>High facilitation and action learning</i> (n=12)				12
Total	1 (3%)	4 (10%)	6 (16%)	27 (71%)

The previous experience of the external facilitator was a factor in how they perceived and therefore reported enablers to the implementation of the GSFCH in practice. One external facilitator had worked in a nursing care home implementing the GSFCH programme, but had not attended the workshops and struggled. Another *local facilitation* experienced external facilitator really valued the workshops and ensured that she and a colleague always attended them with the GSFCH coordinators.

As this research study was looking at facilitation of the GSFCH programme, I attended all the GSFCH workshops to get a sense of the programme being implemented in practice, to understand what information the GSFCH coordinators received at these workshops, to observe who attended and note interactions within the room. The GSFCH workshops were attended by the *high facilitation* groups on day one and the *local facilitation* and *no local facilitation* group on day two. I wrote:

'What a contrast to yesterday...yesterday it was very busy. All the coordinators worked alongside their external facilitators. They all huddled together. The external facilitators helped each other and the nursing care homes. They also worked together with all the GSFCH coordinators from one PCT. There was a feeling of 'being looked after' and 'shared learning'. The

GSFCH coordinators left the workshops with a bit more of an idea about their role and with action plans and knew when their external facilitator would be contacting them to follow them up.

But today. Only one care home had their external facilitator with them. The GSFCH coordinators and their external facilitator sat together all day and worked together. They even travelled to the workshop together. What a blessing for them but a slap in the face for the other nursing care homes. I felt very sorry for all the other GSFCH coordinators watching them steaming ahead..... The Regional Training Centre external facilitators helped the others with action plans but there was no ongoing support. It seemed so disappointing that only one of the 10 'usual' group external facilitators made time to attend. Though, perhaps that may have made the experience worse for those without any external facilitator who were looking on.' [Researcher]

Working together seemed to set the agenda for the time between the GSFCH workshops. Several of the *no local facilitation* GSFCH coordinators commented on how fortunate the others who had external facilitators had been. An enormous amount of information was provided at each workshop: *'Initially there was huge panic and they just thought they couldn't do it, they couldn't see the wood for the tree.'* [F2]. Therefore, the external facilitators' role sometimes involved slowing the GSFCH coordinators down. There was a need to take time to fully implement one aspect of the programme well:

'Erm, I think they tried to see GSF as a whole rather than starting with bite-size pieces. That's one of my favourite phrases, 'We start with bite-size pieces of GSF.' It's like putting everybody's name down on a piece of paper and

that's the start of your register. You know, let's make this simple; let's not make it complicated. ' [F2]

Encouraging the GSFCH coordinator to slow down was easier when they had been present alongside them in the workshop and helped them action plan.

7.6.4.4.2: The external facilitator investing time to establish a relationship with the nursing care home

Some external facilitators highlighted that their role had been made easier because of prior established good relationships with the nursing care home (Table 7.10).

Where this relationship did not pre-exist, it had taken time for the external facilitator to engage. Nursing care homes are visited by many external monitoring agents including their owner, Care Quality Commission and auditors. Seeing the external facilitator as an external professional who was not there to monitor them, but to support them, was a new concept to many (see Box 7.2).

Box 7.2: The external facilitator building relationships with staff in the nursing care home

'I would say the most, the major thing personally, I would say, is about building up relationships that, within the homes, As in I'm ... not monitoring them, I'm there to support them.' [F10]

'It's taken us a long time to build up trust. Erm to get erm homes to open their doors to us and to realise that we're not sitting in judgement on anybody.' [F14]

'I think that, that helped me to get to know the home and being trusted to go in. I wasn't going in as another trouble-shooter which is I think, they often see people, not in authority, but people that are going out facilitating or, erm, inspecting. They see that as an authoritarian role. Therefore I'm going out to criticise what they're doing and when they realised I wasn't, I was out there to help support them and to enable them, I think we're on a much different relationship.' [F3]

One external facilitator felt strongly that to be an external facilitator you needed to be believable. To achieve this, they found previous experience of working in a nursing care home helpful. The nursing care homes she was working with respected her because she understood the context in which they were working and trying to implement change.

Throughout the two year programme, the external facilitators recorded the time they spent with the GSFCH coordinators within each nursing care home. Time spent may have contributed to relationship building between the external facilitator and the nursing care home staff. The mean face-to-face facilitation time with any GSFCH coordinator varied but was considerably higher in the *high facilitation* groups.

- *local facilitation* - 2 hours and 25 minutes
- *High facilitation* - 16 hours and 34 minutes
- *High facilitation and action learning* - 24 hours and 19 minutes

7.6.4.4.3: 'Being present' in the nursing care home

'Being present' was one of the three identified approaches to facilitation. 'Being present' also was an identifiable factor that enabled the implementation of the GSFCH programme into practice. Where external facilitators made particular use of role modelling this would not have been possible if they had not visited (Table 7.10). This consisted of time that the external facilitators simply recorded as time they spent 'role modelling'. However it also includes time where the external facilitators had specified exactly what it was they role modelled. Two activities - undertaking Significant Event Analysis (SEA) and coding meetings were previously identified as being specifically role modelled by the external facilitators. Throughout the two-year

programme, the mean face-to-face facilitation time with a role modelling component was:

Local facilitation - mean 55 minutes (range 0 to 5¼)

High facilitation - mean 15 hours and 44 minutes (range 0 to 57 hours)

High facilitation and action learning - mean 21hours and 49 minutes (range 7 to 46 hours 40 minutes)

The time spent on role modelling was greatest in the *high facilitation* groups because of a ‘being present’ approach to facilitation. However, ‘being present’ would not have inevitably led to the time-spent in this activity. It was provided because the external facilitators had chosen to invest their time in this way. Where this had not occurred the focus of facilitation was one of education (Figure 7.11)

7.7: Conclusion

Three approaches to facilitation of the GSFCH were identified: ‘as requested’ facilitation: ‘fitting it in’ facilitation: and, ‘being present’ facilitation. The approach impacted on both the delivery of, and receipt of facilitation, during the Implementation Phase of the GSFCH. The use of information from a variety of perspectives of people working within the system, to implement the GSFCH programme, provided a comprehensive interpretation. The GSFCH coordinators, nursing care home managers and the external facilitations collectively identified four factors: internal resources, putting systems into place, developing internal relationships within the nursing care home and building external partnerships that, when present, enabled the implementation of this phase of the GSFCH programme and where absent acted as barriers.

The next chapter develops understanding of facilitation in relation to the final phase, the Consolidation Phase, of the GSFCH programme. Consideration is also given to the provision of facilitation on completion of the two-year GSFCH programme.

Chapter Eight - The Consolidation Phase: between workshop four and accreditation

The third and final phase of the GSFCH programme is referred to as the Consolidation Phase. Details of the participants who actually took part in this final phase of the programme, are reported here. This information is from the 37 nursing care homes that were still operational at the end of the two year programme.

Following this the factors identified by the study participants that influenced the implementation of the Consolidation Phase and therefore the GSFCH programme are described. Finally, the participants' views on specific aspects are given. The nursing care home managers shared their views about the role of facilitation when the GSFCH programme was completed and they and the GSFCH coordinators identified any gaps in the implementation of the GSFCH programme completion that they perceived remained in practice. The external facilitators were asked, in light of their experience, to describe how they believed the GSFCH programme should be facilitated. These aspects are explored in detail.

8.1: The study participants taking part in the Consolidation Phase

Staff turnover meant, for some nursing care homes, that participants completing the Consolidation Phase of the GSFCH programme were not the same as those taking part in the Preliminary and Implementation Phases of the programme.

8.1.1: The nursing care home managers

The four facilitation groups had different experiences in relation to stability of their nursing care home managers. In the *no local facilitation* group no nursing care home

managers changed post whereas at least 50% of the nursing care home managers changed as many as five times, in the *high facilitation* and *high facilitation and action learning* groups (Table 8.1).

Table 8.1: Changes in nursing care home manager during the GSFCH programme

Facilitation group	Number of nursing care homes where the nursing care home manager did not change during study
<i>No local facilitation</i> (n=5)	5
<i>Local facilitation</i> (n=9)	5
<i>High facilitation</i> (n=12)	5
<i>High facilitation and action learning</i> (n=12)	6

At the start of the study, within 23 of the 38 nursing care homes, the nursing care home manager took on the role of a GSFCH coordinator. However, only 17 nursing care home managers retained this role for longer than six months (Table 8.2). There were a higher proportion of the nursing care home managers continuing this role in the *no local facilitation* and *local facilitation* groups. Only n=2 (17%) of nursing care home managers in the *high facilitation and action learning* group were GSFCH coordinators for six months or longer. However, within this group the nursing care home managers had committed to attend action learning for the first year of the GSFCH programme.

Table 8.2: Nursing care home manager was a GSFCH coordinator for longer than six months

Facilitation group	Nursing care home manager was a GSFCH coordinator for six months or longer (n=38)
<i>No local facilitation (n=5)</i>	4
<i>Local facilitation (n=9)</i>	5
<i>High facilitation (n=12)</i>	6
<i>High facilitation and action learning (n=12)</i>	2
Total	17

8.1.2: The GSFCH coordinators

During the two year study period, a number of the GSFCH coordinators left the nursing care home where they worked, changed role in the nursing care home or opted out of being a GSFCH coordinator. This meant there were a total of 126 GSFCH coordinators involved across the study.

By the end of the two year programme, only 11 of the nursing care homes (30%) had retained their initial two GSFCH coordinators (Table 8.3). There were 64 GSFCH coordinators present at the end of the study.

Table 8.3: Nursing care homes with the same GSFCH coordinators at the start and at the end of the study

Facilitation group	Number of nursing care homes where GSFCH coordinators did not change (n=37)
<i>No local facilitation (n=5)</i>	1
<i>Local facilitation (n=9)</i>	3
<i>High facilitation (n=12)</i>	2
<i>High facilitation and action learning (n=12)</i>	5
Total	11

Their number varied across the participating nursing care homes from one nursing care home which had no GSFCH coordinators in place at the end of the study, to two nursing care homes that had increased their GSFCH coordinators to three (Table 8.4).

Table 8.4: GSFCH coordinators in post at the end of the study

Facilitation group	Number of coordinators present in the nursing care home at the end of the study (n=37)			
	0	1	2	3
<i>No local facilitation</i> (n=5)	0	0	5	
<i>Local facilitation</i> (n=9)	1	2	5	1
<i>High facilitation</i> (n=12)	0	5	6	0
<i>High facilitation and action learning</i> (n=12)	0	3	8	1
Total	1 (3%)	10 (27%)	24 (65%)	2 (5%)

By the end of the study only 18 (49%) of the nursing care homes still had GSFCH coordinator/s in post who had attended all four of the GSFCH workshops (Table 8.5). Six nursing care homes had no GSFCH coordinators in post who had attended the GSFCH workshops (Table 8.5).

Table 8.5: Nursing care homes with GSFCH coordinator/s in post at the end of the study who had attended any of the GSFCH workshops

Facilitation group	Number of GSFCH workshops that any GSFCH coordinators attended (n=37)				
	0	1	2	3	4
<i>No local facilitation</i> (n=5)	1			1	3
<i>Local facilitation</i> (n=9)	5		1	3	
<i>High facilitation</i> (n=12)		1	4	2	4
<i>High facilitation and action learning</i> (n=12)				1	11
Total	6 (16%)	1 (3%)	5 (13%)	7 (19%)	18 (49%)

This suggests that the importance of the GSF Central Team recommendation (Gold Standards Framework Centre CIC 2011) that the external facilitator attending the GSFCH workshops extends beyond working alongside the GSFCH coordinators. They may actually be the only individuals attached to a nursing care home participating in the programme who had actually attended it and so will have the greatest clarity about the action plans that needed to be implemented.

8.1.3: The external facilitators

Over 80% of the participating nursing care homes with *local facilitation* kept their original external facilitator throughout the GSFCH programme. At the time of interview, external facilitators within the *local facilitation* group were facilitating or had experience of facilitating, between one and 18 nursing care homes. For three external facilitators, their GSFCH external facilitation experience remained in relation to one single nursing care home. In contrast the external facilitators within the two *high facilitation* groups, at the time of interview, reported engagement with three to 13 nursing care homes. Their opportunity to provide facilitation, and gain experience in this role, had increased.

8.2: The experience of providing and receiving facilitation during the Consolidation Phase

As with the earlier phases of the GSFCH programme, facilitation during the Consolidation Phase occurred via two possible sources: the Regional Training Centre and where present, the external facilitator.

In the Consolidation Phase the GSFCH coordinators in all groups were invited to an accreditation workshop. This was the only facilitated activity, initiated by the Regional Training Centre to be offered in the second year of the programme.

For all groups, the level of facilitation provided, diminished over the two year programme. A nursing care home within the *local facilitation* group (LF6) and two of the nursing care homes in *the no local facilitation* group (NLF4 and NLF9) had no facilitation provided to them at all, in the second year of the programme. The majority of all three groups with access to an external facilitator, continued to be supported by them during the second year.

Within both *high facilitation* groups, there was a notable change in the format of the facilitation in the Consolidation Phase. Facilitation was no longer solely provided to the GSFCH coordinator and nursing care home manager, but instead directed towards all staff in the nursing care home (Table 8.6).

All the nursing care homes in both the *high facilitation* groups participated in local network forums, in the second year of the programme (Table 8.6). Five nursing care homes (36%) in the *local facilitation* group also participated in a similar initiative within their local areas. However, the number of nursing care homes in the *high facilitation* groups that participated in the other components identified as *high facilitation* (induction days for new staff, Macmillan 'Foundations in Palliative Care for Care Homes' training and role modelling) was considerably higher.

Table 8.6: Receipt of *high facilitation* by the nursing care home staff in the second year

<i>No local and local facilitation</i> nursing care homes divided by facilitation groups (n=14)	Formation of local nursing care home network forums	Induction days for new staff	Macmillan ‘Foundations in Palliative Care for Care Homes’ Training	Further role modelling
<i>No local facilitation</i> (n=5)	0	0	1	0
<i>Local facilitation</i> (n=9)	5	0	0	0
Total n=14	5	0	1	0
<i>High facilitation</i> nursing care homes divided by facilitation groups (n=23)	Formation of local nursing care home network forums	Induction days for new staff local nursing care home network forums	Macmillan ‘Foundations in Palliative Care for Care Homes’ Training local nursing care home network forums	Further role modelling
<i>High facilitation</i> (n=11)	11	3	5	3
<i>High facilitation and action learning</i> (n=12)	12	5	8	2
Total n=23	23	8	13	5

* the nursing care home manager facilitated this independently and internally through their staff

Despite tremendous efforts one nursing care home (NLF1) had been unsuccessful in obtaining the assistance of an external facilitator. Here, the nursing care home manager taught staff members the Macmillan ‘Foundations in Palliative Care for Care Homes’ training, in the Implementation Phase of the GSFCH programme (see 7.6.1). These staff then taught the Macmillan ‘Foundations in Palliative Care for Care Homes’ training to other staff holding each workshop, a total of five times in this phase of the GSFCH programme.

8.3: Factors impacting on the Consolidation Phase - completing and sustaining the GSFCH programme

There were two factors identified that contributed to the Consolidation Phase of the GSFCH programme that were important to have in place (Figure 8.1). These were having:

- evidence of change
- a plan to sustain the GSFCH programme in practice

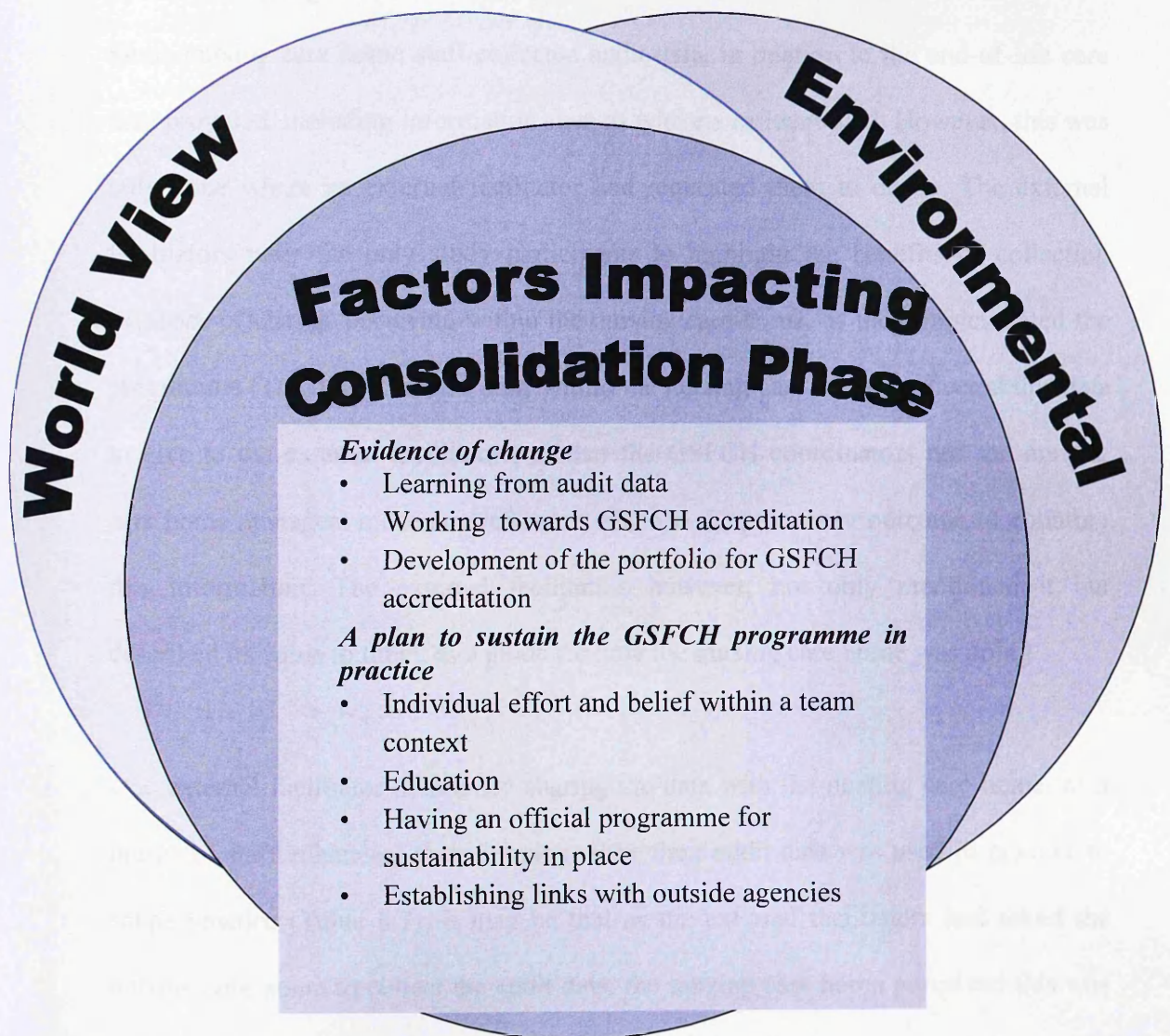


Figure 8.1: Factors impacting on the Consolidation Phase of the GSFCH programme

8.3.1: Evidence of change

There were three sub-themes identified by the GSFCH coordinators and/or external facilitators that related to having evidence of change at the end of the programme:

- learning from audit data
- working towards GSFCH accreditation
- development of the portfolio for GSFCH accreditation

8.3.1.1: Learning from audit data

Some nursing care home staff collected audit data, in relation to the end-of-life care they provided, including information such as where a resident died. However, this was only done where an external facilitator had requested them to do so. The external facilitators were the only study participants to highlight the benefits of collecting evidence of change occurring within the nursing care home, as they implemented the programme (Table 8.7). Whilst staff within the nursing care homes collected this data to give to the external facilitators, neither the GSFCH coordinators nor the nursing care home managers made any reference either to the process or outcome of collating this information. The external facilitators however, not only mentioned it but described its value to them, as a guide for how the nursing care home was doing.

One external facilitator mentioned sharing the data with the nursing care home, as a means of staff enhancing their learning. Here their audit data was used in practice to shape practice (Table 8.7). It may be that as the external facilitators had asked the nursing care home to collect the audit data, the nursing care home perceived this was data owned by the external facilitator. It seemed once the data was handed over this information was not considered again suggesting the majority of the nursing care

home staff had not seen this as valuable information. This was perhaps a missed opportunity of learning. Measurable data has been suggested to be valuable when implementing change (Kitson et al 1998). In this situation having measurable outcomes from implementing the GSFCH programme would be data they could have learnt from, to see what they were doing well and where they could improve.

8.3.1.2: Working towards GSFCH accreditation

Accreditation is the final stage of the Consolidation Phase of the GSFCH programme. However, without evidence of implementing the GSFCH programme, the nursing care homes would have been unable to construct a portfolio to submit for accreditation.

Taking into consideration the findings from the Implementation Phase of the GSFCH where the *no local facilitation* group had no reported use of coding meetings, reflective practice or use of specific GSFCH documentation, GSFCH accreditation was not mentioned at all. Within the *local facilitation* group there were few references made. The *high facilitation and action learning* group were the only facilitation group to report that forging links with other nursing care homes helped them with this process of working towards GSFCH accreditation (Table 8.7).

Table 8.7: Enablers or barriers to completing the GSFCH programme

Identified to be important to completing the GSFCH programme	Act as an <u>enabler</u> to completing the GSFCH programme	Act as a <u>barrier</u> to completing the GSFCH programme
<p>Learning from audit data</p> <p>Having evidence of change</p>	<p>'...to do something with those figures and take them back to it, to them, I've tried, I think I've got better at doing that over the time, because actually it's something really tangible that you can use with them...and it's very helpful to show them, you know, things that have got better or that they're doing more of, as well as, erm, you know, things that aren't improving or have got, you know, tailed off a little bit, or whatever..' [F6]</p>	<p>'I think their, their death rate over the last two years has stayed, erm, just about the same. And from memory it was something like 66, 67 per cent- which isn't dreadful-but it would be nice to, there've been a number, a good number of residents there that should have stayed in the nursing home.' [F6]</p> <p>'Whilst I consider we deliver 'high' standards of end-of-life care we do not have all the documentation required in place in order to be able to prove this.' [M.NLF12.000]</p>
<p>Working towards GSFCH accreditation</p>	<p>'...we are also working towards accreditation for the GSF.' [C.LF14.001]</p> <p>'It has been helpful to see folders of other homes that have gone through the process.' [C.HF+AL2.000]</p> <p>'So, now, January-February-March, until they, I need to go in there at least every two weeks minimum... To help them with the portfolio.' [F1]</p> <p>'...and if I'm free, if I'm going around there...last week I went to a coding meeting, erm...I think essentially now my role is helping with the portfolio and overseeing that.' [F2]</p>	<p>'If they had to do a portfolio tomorrow, they have got evidence, but it's not embedded. You know, it's no good having a piece of paper that's not, they can't say it's working.' [F3]</p> <p>'...and didn't know they had a portfolio: nobody had seen it, and it was locked in the office, because there was ownership. And when...again...and that's, you know, why I had said to the managers, 'You know, you need to share this information. You need to get the staff to take little jobs, little parts to play...' [F11]</p>

The portfolio that needed to be compiled as evidence for GSFCH accreditation wasn't always viewed positively by the external facilitator. Two external facilitators commented that whilst the nursing care home had evidence of change in their portfolio, the GSFCH programme wasn't actually embedded into the culture of the nursing care home (Table 8.7). What is clear however is that the construction of the portfolio was time consuming and took effort both from the nursing care home staff and support from the external facilitator. The delivery of facilitation in both the *high facilitation* groups, during this Consolidation Phase, included the development of local nursing care home network forums and the role modelling of complex situations in the nursing care home. When the nursing care home was applying for accreditation, this often led the external facilitators to increase their input in terms of visits, in order to assist them with their portfolio development and submission (Table 8.7).

8.3.1.3: Development of the portfolio for GSFCH accreditation

Despite the enormity of portfolio preparation, it represented the end of the GSFCH programme and 17 of the participating nursing care homes submitted this for accreditation (Figure 8.2). In the *no local facilitation* group, one nursing care home had become accredited. This was the nursing care home where the nursing care home manager had acted as an internal facilitator and driven the GSFCH programme forward throughout every phase. All the *local facilitation* nursing care homes still needed to complete the accreditation process. Three had applied for accreditation and completed their portfolio but they had all been deferred i.e. needed to resubmit following further work (Figure 8.2). One nursing care home had repeated this process and been deferred for a second time.

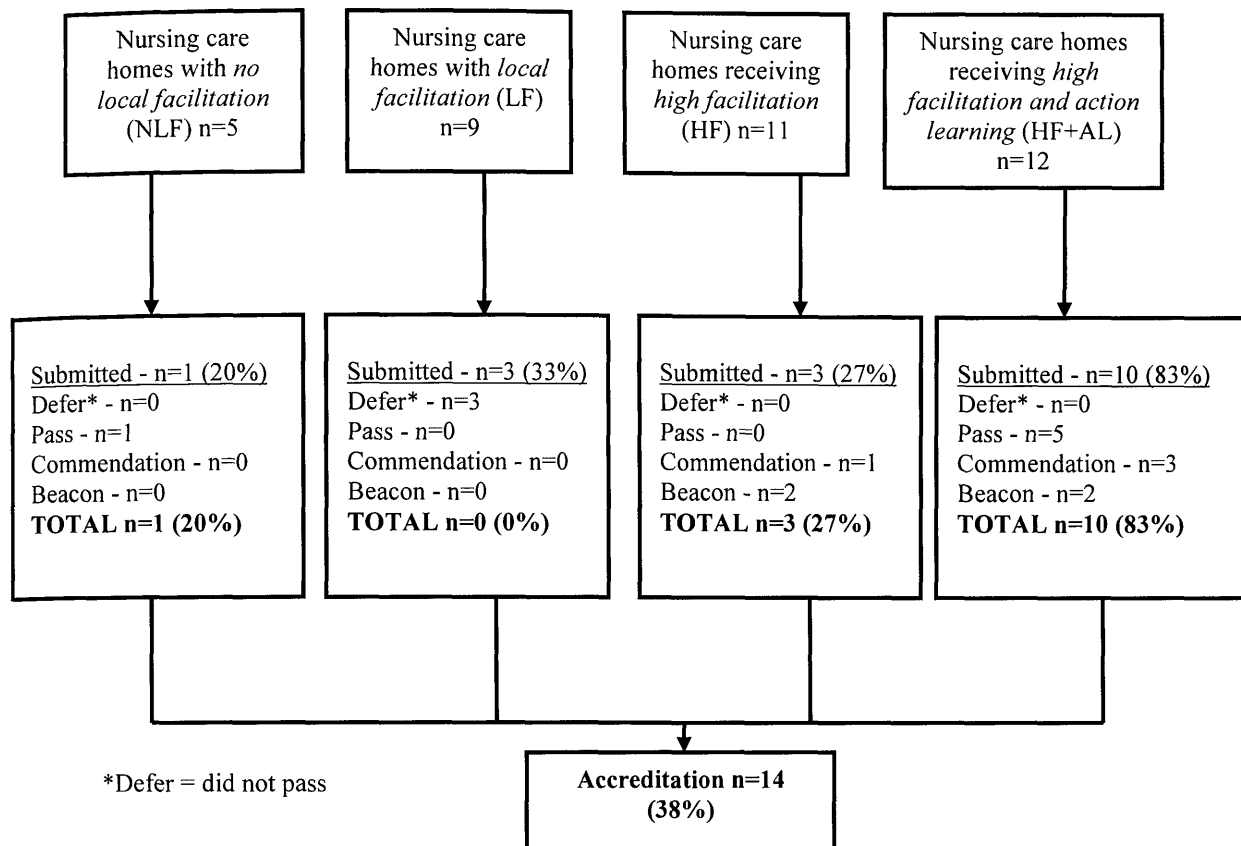


Figure 8.2: Accreditation status of the participating nursing care homes

In both the *high facilitation* groups, varying percentages of nursing care homes had completed and submitted portfolios for accreditation. Eighty-three percent of the nursing care homes in the *high facilitation and action learning* group achieved GSFCH accreditation and 27% in the *high facilitation* group. In both these groups, all nursing care homes that completed the application for accreditation through submitting their portfolio of evidence and having an external assessment visit, passed.

For the 37 nursing care homes still open at the end of the GSFCH programme, there was a significant association between the type of facilitation that had been provided and their accreditation status, Fisher's exact test $X^2(2) = 16.504, p < .000$.

The external facilitator activity logs were all reviewed. As time had been specifically designated by the external facilitators in the *high facilitation* groups to help the staff in the nursing care homes with the GSFCH accreditation, this formed a new variable.

Logistical regression was used to analyse variables that may have contributed to successful accreditation. The qualitative data highlighted the importance of support by the nursing care home manager as well as the GSFCH coordinator, when implementing the GSFCH programme. The following variables were therefore analysed in relation to successful accreditation:

- Time spent by the external facilitators with any member of the nursing care home team specifically designated for ‘accreditation’
- Attendance by any member of the nursing care home at the accreditation workshop
- Time spent by the external facilitator with the nursing care home manager:
 - The number of action learning sets the nursing care home manager had attended
 - The number of times the nursing care home manager attended any GSFCH event
 - Total time the nursing care home manager attended any GSFCH event including AL
- Time spent by the external facilitator with the GSFCH coordinator:
 - The number of times the GSFCH coordinator attended any event
 - Total time given to the GSFCH coordinator – face-to-face

From this initial analysis of the identified variables four were identified as highly significant (Table 8.8).

Table 8.8: Logistic regression of the four factors identified as highly significant in relation to successful accreditation

Variable	<i>P</i>
Time spent by the external facilitators with any member of the nursing care home team specifically designated for ‘accreditation’	0.003
The number of action learning sets the nursing care home manager had attended	0.004
The number of times the GSFCH coordinator attended any event	0.003
Total time given to the GSFCH coordinator - face-to-face	0.004

Whilst other factors may have influenced the probability of a nursing care home successfully becoming accredited, what this does show is that supporting the nursing care home managers, supporting the GSFCH coordinators and the provision of designated time by an external facilitator for accreditation was more important than attendance at the GSFCH accreditation workshop. It would appear that attendance at the accreditation workshop was not a significant factor. As this is the only time officially set aside in the GSFCH programme for the nursing care homes in relation to accreditation this needs reviewing.

The relative importance of these four variables was established by using the bootstrap technique (Barber and Thompson 2000 and Thompson and Barber 2000). Its use resulted in a larger sample. This enabled the probability of a nursing care home becoming accredited to be predicted and confidence levels to be plotted. When taken together, bootstrapping the initial four variables reduced those of interest to two:

- Time spent by the external facilitators with any member of the nursing care home team specifically designated for ‘accreditation’

- The number of action learning sets the nursing care home manager had attended

Of these the time designated for accreditation ($p < .01257$) was the only significant variable (number of action learning $p < .07592$). However, as these two variables were the most significant when predicting the probability of a nursing care home gaining accreditation, they were looked at in relation to one another (Figure 8.3).

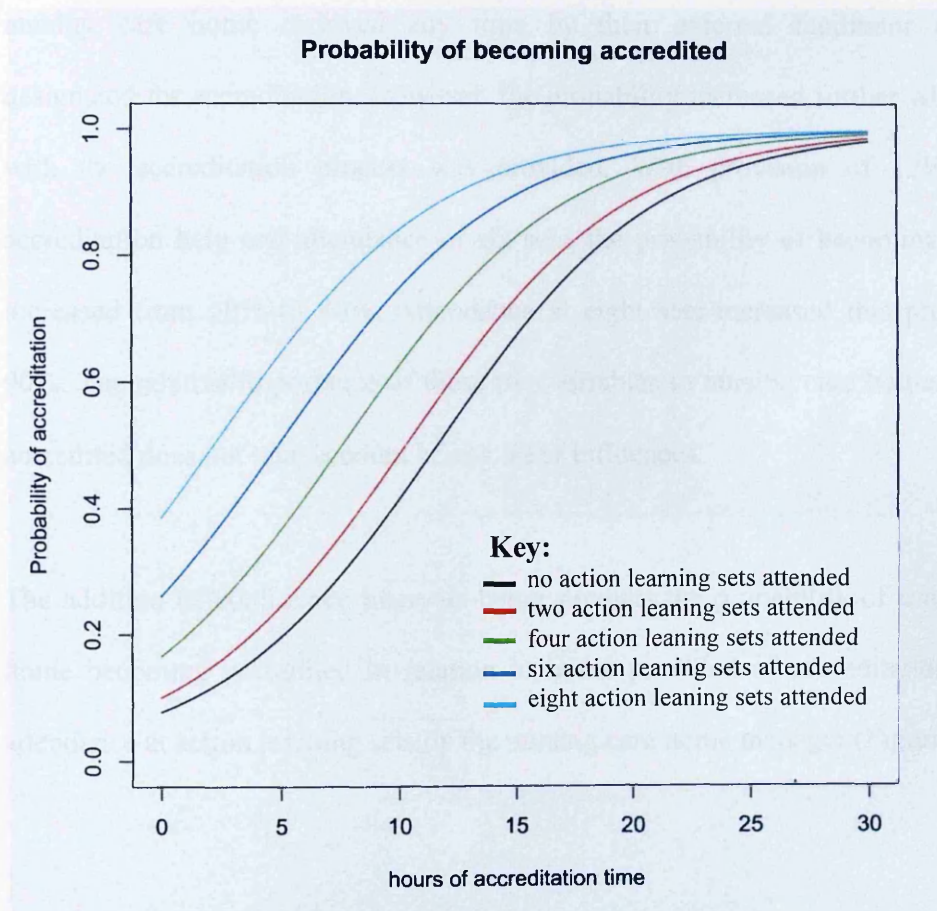


Figure 8.3: Predicted probability of becoming accredited - in relation to hours of accreditation time spent with an external facilitator and number of action learning sets attended

Where the nursing care home manager attended no action learning sets, but the external facilitator spent 25 hours or more with any member of the nursing care home, that was specifically designated as accreditation, the nursing care home was almost certain to successfully become accredited (Figure 8.3). When 12½ hours of facilitation was provided they stood a 50% chance of gaining successful accreditation.

The probability of the nursing care home becoming accredited was greater when the nursing care home manager attended action learning sets regardless of whether the nursing care home received any time by their external facilitator specifically designated for accreditation. However, the probability increased further when support with the accreditation process was provided. With provision of 12½ hours of accreditation help and attendance of six sets, the probability of becoming accredited increased from 50% to 80%. Attendance at eight sets increased this probability to 90%. The relative importance of these two variables to nursing care homes becoming accredited does not take account of any other influences.

The addition of confidence intervals better predicts the probability of a nursing care home becoming accredited in relation to hours provided of accreditation time and attendance at action learning sets by the nursing care home manager (Figures 8.4-8.6).

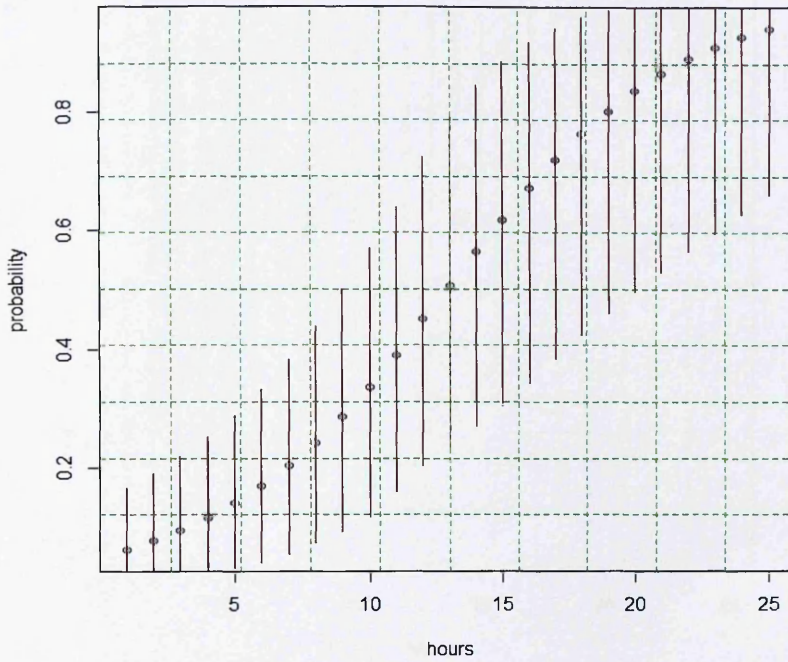


Figure 8.4: Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended no action learning sets

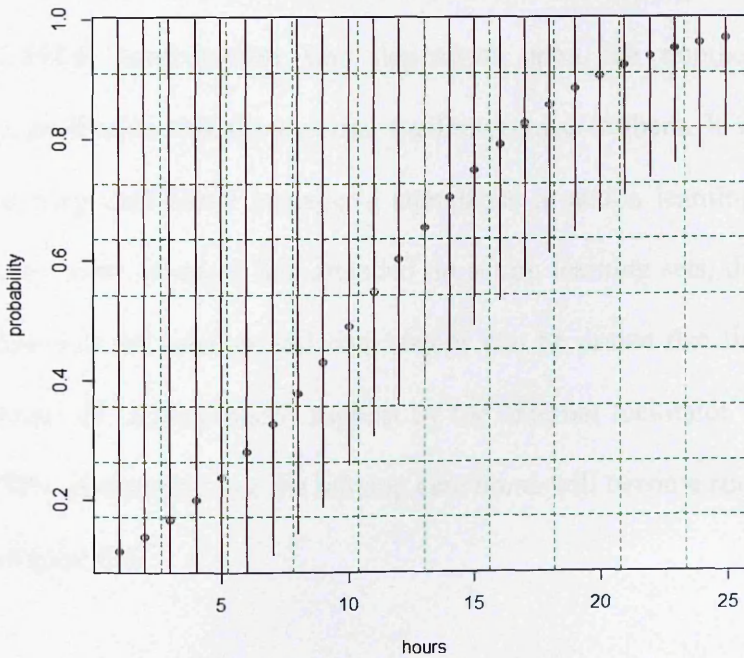


Figure 8.5: Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended two action learning sets

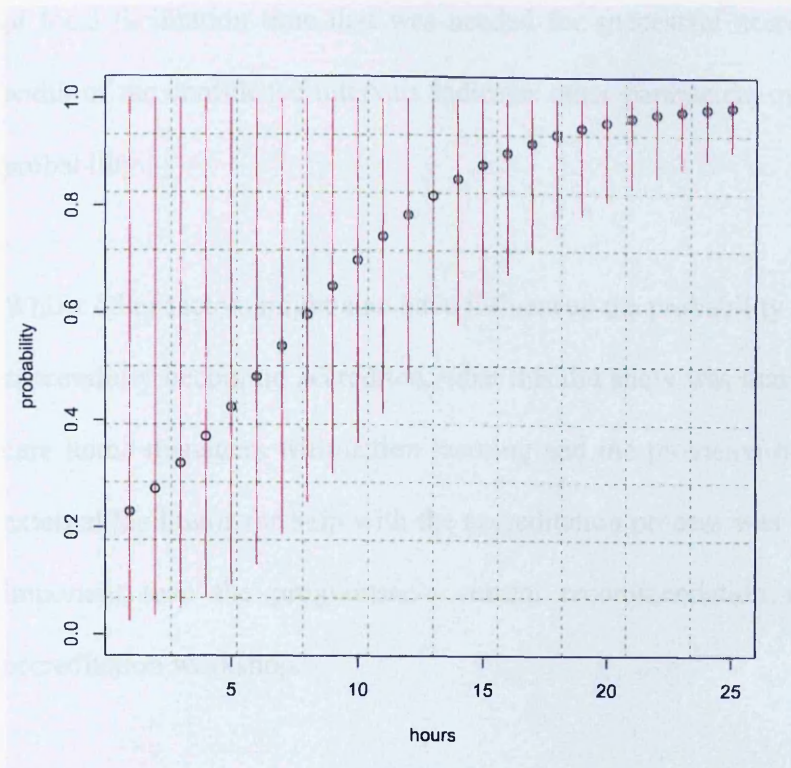


Figure 8.6: Predicted probability of becoming accredited - hours of external facilitator accreditation support when the nursing care home manager attended five action learning sets

Figures 8.4-8.6 show that the probability of the nursing care home gaining successful GSFCH accreditation was dependent upon the number of hours of time on accreditation that the external facilitator gave to them. It was also increased, by the nursing care home manager's attendance at action learning sets. Where the nursing care home manager had attended no action learning sets, the width of the confidence intervals are smaller and conclusions can be drawn that the provision of at least 20 hours of 'accreditation' support by the external facilitator will lead to a greater than 50% probability that the nursing care home will become successfully accredited (Figure 8.4).

The confidence levels in Figures 8.5-8.6 are much wider. These figures suggest that the more action learning sets the nursing care home manager attended, the less hours

of local facilitation time that was needed for successful accreditation. However the width of the confidence intervals indicates other parameters might be influencing the probability.

Whilst other factors might also have influenced the probability of a nursing care home successfully becoming accredited, what this did show was that supporting the nursing care home managers with action learning and the provision of designated time by an external facilitator for help with the accreditation process was important. It was more important than the programme's current recommendation to attend the GSFCH accreditation workshop.

8.3.2: A plan to sustain the GSFCH programme in practice

The GSFCH programme aims to initiate, and develop the delivery of high quality end-of-life care practice in nursing care homes. However such change takes time:

'And some kind of programme that will, that's not just a drop in a bucket, that will actually be able to be sustained and embedded 'cos (sighing) you need more than one year to change culture in a care home.' [F1]

Sustainability, maintaining all the elements of the programme in practice, would only occur after completion of the programme, which meant gaining GSFCH accreditation. Until then the process remains one of implementation. One of the *local facilitation* external facilitators recognised this position. When asked about sustainability, she believed that the completion of the accreditation process was the beginning not the end.

'one of the things is to really now hope that it doesn't finish once you submit your portfolio, like, you know, like, I think it's just the beginning of...well, I

did my nurse, my prescribing last year and that's just...you know, that portfolio was like giving birth but actually, it wasn't, it was, that was just giving me some grounding, wasn't it? And it's not that at all, it's, it's what comes after.' [F11]

How a nursing care home intends to maintain such change in practice after completion of this programme, is one of the standards they need to evidence, within the accreditation portfolio. Therefore, nursing care homes who become accredited will have in place a written plan for sustainability. Accreditation however, is optional and so is not undertaken by every nursing care home taking part in the GSFCH programme.

There were four sub-themes, some similar to other phases of the GSFCH, identified by the GSFCH coordinators and external facilitators which related to sustainability of the programme:

- Individual effort and belief within a team context
- Education
- Having an official programme for sustainability in place
- Establishing links with outside agencies

8.3.2.1: Individual effort and belief within a team context

Sustainability was seen by the *local facilitation* and *no local facilitation* groups to be the responsibility of individuals. Rather than any specific reference to end-of-life care, the emphasis was on individuals providing a high standard of care for each resident (Table 8.9). It was the practice of each individual staff member's that was important.

For one GSFCH coordinator in the *high facilitation* group sustainability rested upon individuals seeing a difference in care that they believed to be important (see Box 8.1).

Box 8.1: Sustainability of the GSFCH programme: Individual perception of improvement in care

'Observation of the difference that has been observed to residents relatives and staff following recent deaths when compared to end-of-life care prior to the GSFCH.' [C.LF14.001]

'....and care elderly people getting is improved.' [C.LF5.077]

'Reduced unnecessary hospital admissions.....co-ordinated everything made life easier for the clients and their families.' [C.HF9.002]

Whilst individual effort and individual belief was seen as an enabler of sustainability by the GSFCH coordinator, an external facilitator saw this as detrimental to the sustainability of the programme as sustainability of the programme would be at risk if this one person left the nursing care home (Table 8.9). As discussed earlier, implementation of the GSFCH requires cultural change; if the programme is truly implemented sustaining it should be part of everyone's practice not the practice of one individual.

Alongside individual practice, there was also acknowledgement by all four groups that teamwork was important if the GSFCH programme was to be sustained in practice. This had previously been mentioned as important in the Implementation Phase (see 7.6.3). The *no local facilitation* group only mentioned this in a broad context *'All staff are on board and supporting the embedding of GFSCCH.'* [C.NLF9.056]

Table 8.9: Enablers or barriers to sustaining the GSFCH programme

Identified to be important to sustaining the GSFCH programme	Act as an <u>enabler</u> to sustaining the GSFCH programme	Act as a <u>barrier</u> to sustaining the GSFCH programme
Sustaining change	<p>'Devotion to the career and personal choice to remain in constant practice of what has been learned.' [C.LF5.001]</p> <p>'Passion and support of manager.' [C.LF2.001]</p> <p>'Involving relatives/residents in the meetings.' [C.HF7.000]</p>	<p>'...she's been...trying to get the advance care plans done, the DNARs, as I said, she's been struggling with a bit more-but she is trying to get the systems in place and get everything in the notes so that it's all clear...I can't remember their home death rate, but it's certainly improved from one year to the next and hopefully will continue to increase. But it is down to the determination of, of one person...' [F6]</p>
Education	<p>'because, erm, part of my role is education were just doing....looking at...education at the moment, and nursing homes will feature very heavily into that, so, yeah, the link wont just go.' [F7]</p> <p>'Continuous training, workshops, follow ups. Our care staff constantly changing. We need continuity of these efforts.' [C.HF+AL10.068]</p>	<p>'...but it's only available until the end of March because it's basically just trying to use up the money... so in, what, four weeks, you're gonna try and offer, 'cos they were talking about offering staff within the, nursing homes, the care homes, to access E-learning, but what's the use of that in four...what can you do in four weeks? Someone's gonna start doing some E-learning and they're halfway through but, oh, the end of March, 'Oh I'm sorry but, you know, you can't do it anymore...and would that then put them off actually wanting to do anything else?' [F10]</p>
Having an official programme for sustainability Links with outside agencies	<p>'Management have decided to include questions on GSF in interview form.' [C.HF+AL10.001]</p> <p>'Agenda item at all meetings.' [C.HF+AL5.000]</p> <p>'To have a facilitator.' [C.NLF11.008]</p> <p>'Networking, keep the program in top gear.' [C.HF+AL6.001]</p> <p>'Continued support from the links we have forged while introducing the GSFCH.' [C.LF14.001]</p>	<p>'we're having to be quite ruthless because I've got limited time...They're supposed to be having a meeting every week because they're a big home...And then you get there and it's: "I don't know what we're discussing today." No one, the reminiscence floor hasn't had a meeting I don't think for three months because there's no one committed on the reminiscence floor to do this.' [F3]</p>

The *local facilitation* and both *high facilitation* groups identified specific individuals within the team whom they believed were essential to have on board, in order to sustain the programme in practice. The nursing care home manager was identified by all groups, with involvement of the relatives with families, friends and residents additionally mentioned by both the *high facilitation* groups (Table 8.9). One external facilitator was hopeful that given time within the nursing care homes the GSFCH coordinators of the GSFCH programme would be able to take on the sustainability role:

'So I hope they will be self-sustaining and that the end-of-life care that the GSF co-ordinators will become sort of champion. Some of the bigger homes have got end-of-life care champions, like they have dignity champions. So I think it will continue because they see such a good benefit in it. They see the positivity of it...I may have some time soon. In a years time I might be thinking, oh, what can I do next?' [F9]

8.3.2.2: Education

The GSFCH coordinators within all four groups recognised the provision of education and training as a core component to sustainability of the GSFCH programme. However, within the *no local facilitation* group, there was no mention of what they believed this training should specifically be about or how often it should be provided. No GSFCH coordinator provided reasons for their view. There was recognition by the *local facilitation* external facilitators that they would need to assume responsibility for sustainability. Training was described as the mechanism they intended to use for achieving this. The GSFCH coordinators in the *local facilitation* and *high facilitation* groups both described education and training as necessary for sustainability of the

programme, but it was the continuous provision of this that was important. The reason they gave for wanting this was to keep staff up-to-date. The education provided needs to be appropriate and sustainable. One external facilitator (F10) gave an example of palliative care e-learning which was available but not sustainable (Table 8.9).

Both *high facilitation* groups were the only groups to acknowledge continuous education and training to be important and articulate the reasons for this. Staff turnover occurred and that meant that new members of staff needed information about the GSFCH programme and for those in post, it was recognised that there was still more that could be learnt (Table 8.9).

8.3.2.3: Having an official programme for sustainability in place

Where the GSFCH programme was mentioned in the *no local facilitation* group it was in relation to implementation of the programme, which suggested that this still needed to be achieved: '*To be able to apply and share what I have learnt.*' [C.NLF12.001] There was no mention within the *no local facilitation* group of an official sustainability programme in place. This may well be because the GSFCH programme was still to be embedded: the need for a sustainability programme had not been recognised.

In the *local facilitation* group, no specific details were provided but there was mention that a structure was put in place to enable sustainability. '*Formal structure now in place to ensure that practice is ongoing and remains embedded.*' [C.LF14.000] As

details of this were not given, it is unclear what this was and if it related to a formal structure within, or external, to the nursing care home.

By the end of the GSFCH programme, both high facilitation groups had an official programme for sustainability in place. Within the *high facilitation* group, there was a sense of individual effort still needing to be made by the GSFCH coordinator to maintain the programme without which, sustainability would not be possible: ‘...enforcement are needed.’ [C.HF12.001] and ‘To continue with GSF needing constant supervision with staff to discuss the resident and their concerns for delivering care to dying residents as some staff find this frightening.’ [C.HF5.063] There was also caution expressed about the external facilitator assuming responsibility for sustainability. They were conscious that if funding ceased, this role would end as well.

Unlike in the *high facilitation* group, the official sustainability programme in the *high facilitation and action learning* group was not described as being dependent on the effort of the individual GSFCH coordinators. The programme was embedded and became usual practice (Table 8.9). However, even with an official sustainability programme in place, there was an anxiety about keeping the GSFCH programme embedded within the nursing care home, after accreditation:

‘And I think because of their pull on time erm sometimes it’s somebody outside the home – you have to be a pretty special person I think if you, you know, you don’t need reminding at times... I think it’s almost like once they’ve gone through the accreditation we shouldn’t let them go. There should be some kind of formal thing. No matter how...you know, gentle that might

be...of course they will be re-accredited in 3 years' time, er and that hasn't happened yet. So it will be interesting to know what homes have still retained the enthusiasm and the, the vision if you like, of improving things.' [F3]

8.3.2.4: Establishing links with outside agencies

All four groups mentioned facilitation as a mechanism for sustainability of the GSFCH programme in practice. Only one GSFCH coordinator in each of the *no local facilitation*, the *local facilitation* and the *high facilitation* groups mentioned access to an external facilitator as a sustainability factor (Table 8.9). Within the *high facilitation and action learning* group, individual effort was not mentioned at all. Sustainability was viewed instead as being a team effort. There was recognition that it occurred through forming support networks with other local nursing care homes '*Interacting with other nursing home to exchange views.'* [C.HF+AL4.092] No other facilitation group mentioned this as a factor of sustainability. Even though the *high facilitation and action learning* groups had established local care home network forums (Table 8.6) external facilitator guidance was still requested: '*Facilitator maybe needs to give us a call or visit may be twice a year.'* [C.HF+AL2.000]

One experienced *local facilitation* external facilitator was very aware of the need to ensure sustainability of the GSFCH programme. She was particularly conscious that she might not always be there to do this:

'For, for erm sustainability...it's actually making sure that if [the current nursing care home manager] was not there for any reason, that there is, the home feels that there is somewhere that they can pull on and actually carry on to support if they hit difficulties and you know, need that onward support.'

With the uncertainty we don't know whether we're going to be there, and it's actually trying to look at some way of perhaps, of being a little bit more erm network wise self-sustaining' [F14]

However, she spoke of her experience with a nursing care home whom she believed, did not want to form networks with other nursing care homes:

'the other home, I think has probably got a little bit of reticence in sharing, although I haven't got any actual documented evidence to support that. I feel there may be a withdrawal due to business erm pressures, feeling that they're needing to take the homes forward but not necessarily sharing things that could actually be utilised by other er businesses.' [F14]

Sustaining the GSFCH in practice was dependent upon the nursing care homes' wider external community, engaging with and valuing the programme. A GSFCH coordinator in the *high facilitation* group suggested that external practitioners knowing about, and becoming committed to the programme, was not their responsibility: *'Doctors in the community to be educated on GSFCH programme to make life easy.'* [C.HF4.003]

There is perhaps a need to ensure that network links are established between those implementing and sustaining end-of-life care programmes as well as for those who are attending them:

'the amount of things that are going on...Each day there seems to be another group of people doing something to do with end-of-life...It's just never-ending. I just think it's almost as if lots of little people all doing their own things, but

there's no very like cohesive one thing.' [F10]

8.4: The role of facilitation after the two year GSFCH programme

At the end of the programme all three facilitation groups wanted more facilitation. However, the GSFCH coordinators of the *local facilitation* group, recognised that they needed an alternative form of facilitation to that which had been provided. They had needed their external facilitator to be present. Being available had not been enough: *'Wanted...regular meetings...I only remember Facilitator 4 attending one workshop and one other meeting at the nursing care home.'* [C.LF2.001] and *'To have regular support would have been beneficial-to 'brain storm' ideas and occasionally lessen the load.'* [C.LF2.001]

As they had not received this, they did not perceive the need for more facilitated help in the experienced format. Instead, there was recognition that linking with other nursing care homes that had been through the GSFCH process would be most valuable:

'Not necessarily a facilitator but having the opportunity to visit or discuss on a 1:1 basis with a coordinator from another home who had successfully gained accreditation.' [C.LF14.000]

The *high facilitation* and *high facilitation and action learning* nursing care homes indicated that they too, would have liked additional facilitation. Interestingly, the facilitation they wanted was not always from the external facilitator, but as a consequence of a perceived lack of support from other external professionals:

'Because we only have GP service. He visits once a week. We have no back up team like the hospice. We are alone and have to think on our feet.'
[C.HF7.028]

A second acknowledgement of the need for ongoing facilitation was in connection with sustainability of the programme. This view was expressed both by individuals new into post and in established roles: *'For sustainability and continuous quality improvement.'* [C.HF+AL3.000] and *'GSFCH coordinator is a new role to me. GSF facilitator's support, advice and help is essential to me for making progress in GSF.'* [C.HF12.000]

For nursing care homes that did not have an external facilitator, staff at the nursing care homes reported that they needed an external facilitator to implement what was learnt at the workshops and to complete the programme through to accreditation:

'It was difficult not having a facilitator...to implement the GSFCH programme and to give support and guidance in preparing our portfolio for the accreditation. For care homes who do not have facilitators the homes should have had some support to prepare their portfolio.' [M.NLF11.000]

8.5: Gaps in relation to the GSFCH implementation

The GSFCH coordinators and nursing care home managers identified a number of gaps that still existed, in relation to the implementation of the GSFCH programme. Gaps existed across all the factors and their sub-themes identified by participants as listed in Figure 8.7. Their identification perhaps highlights the need for ongoing facilitation support.

The *no local facilitation* group viewed responsibility for failure to progress with the implementation of the GSFCH, to be attributable to a lack of facilitation. One nursing care home manager said: *'Felt after finished workshops-what's next?'* [M.LF10.000] Without the workshop structure to guide them and no external facilitator, the direction and drive for the second year of implementation of the programme needed to be by the GSFCH coordinators and the nursing care home. When there was no external facilitator present, this process was described as more difficult or impossible:

'It has been impossible to implement the GSFCH without the support of a facilitator.' [M.NLF12.000]

**Across all Phases:
Worldview
Environmental influences**

Factors influencing the implementation of the GSFCH

Preliminary Phase

Factors with their sub-themes

The level of preparedness for change in the nursing care home

- The 'pre' existing level of care provision
- Having a culture for engagement with new ventures
- Gaining palliative care knowledge prior to the GSFCH workshops commencing
- Creating a support network

Having a reason to undertake this work

- Having a vision

Implementation Phase

Factors and sub-themes

Internal resources

- The GSFCH coordinators motivation
- Continuity of GSFCH coordinators
- Communication processes agreed and workable
- Time to implement action plans

Putting systems into place

- Establishing monthly coding meetings
- Undertaking reflective practice
- Use of specific tools and documentation to guide care

Developing internal relationships within the nursing care home

- Visible senior management support and leadership
- Support for the nursing care home manager
- Staff who know each other, are valued and work together
- Individual staff groups contributing to the implementation of the GSFCH programme

Building external partnerships

- GP engagement and partnership
- Development of partnerships with other professionals
- Local nursing care home support network
- The external facilitator

Consolidation Phase

Factors and sub-themes

Evidence of change

- Learning from audit data
- Working towards GSFCH accreditation
- Development of the portfolio for GSFCH accreditation

A plan to sustain the GSFCH programme in practice

- Individual effort and belief within a team context
- Education
- Having an official programme for sustainability in place
- Establishing links with outside agencies

Figure 8.7: Factors contributing to the implementation of the GSFCH programme

8.6: Vision for a future model of facilitation

The external facilitators were asked to consider in hindsight, if they would have done anything differently and what a future model of facilitation of the GSFCH programme should look like. Not surprisingly, there was support in *local facilitation*, *high facilitation* and the *high facilitation and action learning* groups for the provision of facilitation of the GSFCH programme: *'And I think what's helpful for the homes is to have somebody external that has no agendas other than to see them succeed in the GSF.'* [F13] Interestingly, the *local facilitation* facilitators mentioned that their vision of a model of facilitation for the GSFCH programme would incorporate many of the aspects identified in Figure 8.7.

There was recognition that the external facilitator, as well as the nursing care home staff needed help and support, to implement the GSFCH programme. Recommendations suggested included access to a support group and the provision of clear guidelines, by the GSF central team, about what was expected of them as an external facilitator of the GSFCH programme, so they could meet a known standard.

There were also a surprising number of comments about the accreditation process which is the final component of the GSFCH programme. One external facilitator commented that the grading system in the GSFCH accreditation process should be removed. They viewed this as divisive. There was recognition that few nursing care homes became accredited and perhaps that the process and funding for this needed to be reviewed:

'When you think over a thousand homes have gone through the programme and I think we're up to 150 credited, or 180 credited.... Yeah, so 200 of that,

it's 20%. That doesn't seem right. - what's the reason? Lack of, lack of funding? You can't afford the £1,000 plus it's going to cost you to go for accreditation? Is it support? Is it your proprietors don't want you to do it? I think that needs to be resolved. What's the issue for that? What's the reason why homes aren't going through the accreditation? [F9]

The *high facilitation* and *high facilitation and action learning* external facilitators were supportive of the approach to facilitation that they had been working with. Their views of a future model developed this concept further. They focused on the practicalities of implementation of the GSFCH programme (Table 8.10). This was very different from the 'fitting it in' and 'as requested' groups, when the onus was on them and their role to be proactive in offering support.

One of the external facilitators made a very insightful comment at the end of her interview. It summarised this external facilitator's belief about the future model for implementation of the GSFCH programme. The nursing care home needed to be able to be self-supporting but until this time she believed ongoing support was essential:

'Erm, I think, for now, whilst the processes are still very, very young, I think it's a little bit like a nursery garden, you know, that everything is really, really delicate and that's why any time there's changes, the shoots are just crushed because they're not getting enough time to, they're not getting enough time to really grow. So we're in that time where they, delicate gardening is required until things really become established. Erm, and after that, then I would hope that you'd have – actually you'd grow your own really, but, yes, you'd still have an over-arching access to people, but you

will have hopefully have grown your own system.' [F11]

Table 8.10: The external facilitators' vision for a future model of GSFCH facilitation

GSFCH programme	Comments from 'fitting it in' and 'as requested' external facilitators	Comments from 'being present' external facilitators
Preliminary Phase	<ul style="list-style-type: none"> • Needs to be provided locally • It should be someone's dedicated role • The external facilitator needs to 'be present' in the nursing care home including prior to the first workshop • The external facilitator should be funded • The external facilitator needs experience of the GSFCH programme, palliative care and the nursing care home context • They should have a clinical role 	<ul style="list-style-type: none"> • Good basic care needs to be in place before the GSFCH programme starts • Needs to be prescriptive about the implementation of the GSFCH system at the start • Should help the nursing care home with the choice of GSFCH coordinators at the start of the programme and that the GSFCH coordinators should be changed if they failed to undertake the role
Implementation Phase	<ul style="list-style-type: none"> • Ensure that more than one person is responsible for implementation of the GSFCH within the nursing care home • The external facilitator needs to attend the workshops • Ensures the nursing care homes network and help each other • Use mini significant event analysis 	<ul style="list-style-type: none"> • Write a clear action plan following each visit and plan a subsequent visit • Recognise a large nursing care home would need several GSFCH coordinators • Establish coding meetings on each floor • Visit regularly to establish a relationship • Implement LCP training • Ensure they were firm and led the GSFCH implementation • Having GSFCH coordinators within a variety of disciplines (RGN and HCA) enabled 'peer' and therefore targeted influence • Ensure the GPs and nursing care home manager are critical to the programmes implementation and need to be included • If GP doesn't attend coding meetings ensure there is a recognised mechanism to feedback information to him • Include everyone including the night shift.
Consolidation Phase	<ul style="list-style-type: none"> • Has a plan for sustainability 	<ul style="list-style-type: none"> • Provides support up to and including accreditation • Review evidence of the GSFCH programme being implemented such as documentation/audit role model • Have, introduce and maintain a sustainability plan

8.7: Conclusion

The last three chapters have considered the experience of both those receiving and those providing facilitation throughout the GSFCH programme. Completing this programme required facilitation and when the programme was completed, facilitation was still needed for sustainability. Depending upon their experience of implementing, the programme the participants' belief about where this support should come from varied. Learning from this, and the findings from chapters six and seven are discussed in chapter nine as well as a personal reflection on the process of undertaking this research study.

Chapter Nine – Layers of learning when implementing and sustaining the GSFCH programme

In this chapter I discuss the interpretation of the findings presented in the preceding three chapters. The use of Soft Systems Methodology as the theoretical framework for this study enabled the process of implementation of the GSFCH programme and the role of facilitation within this to be captured. This approach to the study identified that completing and sustaining the GSFCH programme in practice required organisational cultural change. Achieving such change required a whole systems approach that started at the beginning of the programme (Preliminary Phase) and ended with its completion (Consolidation Phase).

Importantly, the use of Soft Systems Methodology identified that work was required in all phases by those providing facilitation (the facilitators or actors), as well as by those individuals receiving it (the staff in the nursing care homes or customers). Here work means engaging with activity (developing skills) in clinical practice, beyond attending the education sessions provided in the GSFCH workshops. It required a 'being present' approach to facilitation rather than an 'as requested' or 'fitting it in' approach. When attempting to understand the implementation of change, all stages of a programme and all roles are important to consider. The results are considered in light of this.

Within this chapter I propose that the organisational cultural change needed to implement the GSFCH programme will only occur with commitment from the participating organisations' internal and external systems. Multi-layered learning is needed for such cultural change to occur in nursing care homes. The nursing care

home staff need to work towards becoming a learning organisation (Senge et al 1994) and perhaps more importantly, establish and become part of not only an *appreciative system* (Vickers 1983)⁷ but an *appreciative learning system*. *Appreciative* here means that those belonging to such a system recognise that there is actual, or potential, benefit to be gained from its membership.

The results obtained suggest that it is multi-layered learning: at an individual level, an organisational level (this included the team or group) and at a systems level that increases the likelihood of a cultural change initiative being successful. External support is needed to achieve this. This was also more likely to be achieved by those nursing care homes supported with a ‘being present’ approach to facilitation. Justification for this proposition is provided as the three identified levels of learning: individual, organisational and systems are explored in turn.

This study was undertaken alongside a CRCT measuring outcomes that arose from implementing the GSFCH programme in relation to facilitation. The mixed methods design of this study identified how completion of the GSFCH programme, through to accreditation, was influenced by the approach of facilitation that was provided. My experience of undertaking this study is considered. Whilst the CRCT and this mixed methods study are separate studies, they are connected, so consideration is given to how these studies’ findings relate to one another. Finally, how the findings of this mixed methods study challenge or resonate with research, in relation to the

⁷ Appreciative learning systems differ from Appreciative Inquiry. Appreciative learning systems in this thesis were a finding. The term ‘appreciative’ emerged from the work of Vickers (1983), and is used to describe human activity that results from ‘experiencing relationships, trying to maintain satisfactory ones and elude unsatisfactory ones’ (Checkland 2005: 287). Appreciative Inquiry is ‘...a theory, a mindset, and an approach to analysis that leads to organizational learning and creativity’ (Watkins and Cooperrider 2000;6). It relates to a philosophy, a research process or a paradigm, not a finding.

implementation of other change initiatives in a nursing care home context, is briefly considered.

9.1: Individual learning: by the GSFCH coordinators, external facilitators and the nursing care home managers

i. The GSFCH coordinators

The GSFCH programme started with the individual learning of the GSFCH coordinators. They attended the GFSCH workshops and learnt about the care needs of nursing care home residents in their last year/s of life (see 2.6.1). The GSFCH coordinators provided the role of an organisational champion (Hendy and Barlow 2011). They, and the knowledge they attained at the start of the programme, through individual learning at the four GSFCH workshops, were essential. However, the systematic literature review (see chapter four) identified that the sole provision of an educational and/or training intervention, within nursing care home settings to support the provision of end-of-life care, would not change practice in this generalist setting.

In the Preliminary Phase of the programme, it was an expected outcome that the GSFCH coordinators inform GPs, other health care providers, residents and relatives as well as the rest of the nursing care home staff of the decision by management to implement this programme (Gold Standards Framework Centre CIC 2011). The showing of the GSFCH DVD, discussion of the programme at relatives' and residents' meetings, all assumed the GSFCH coordinators would have a degree of knowledge about the programme and be able to deal with any queries that arose. This may have been challenging for some GSFCH coordinators (Table 6.6). In acknowledgment of this, the provision of the Macmillan 'Foundations in Palliative Care for Care Homes'

Training to the GSFCH coordinators in both the *high facilitation* groups and in the *no local facilitation* nursing care home, that became accredited, is likely to have supported the GSFCH coordinators and encouraged them to initiate the start of the programme. Without this, they were being asked to initiate a programme with potentially very little individual palliative care knowledge. Berta et al (2010:1331) describes this as: '*equipping staff with the appropriate skills to apply the new knowledge.*' This was also relevant to the external facilitators (see next section).

Individual learning also occurred within the Implementation Phase of the GSFCH programme. Whilst the four GSFCH workshops were intended to provide nine months of structured individual learning for the GSFCH coordinators, this did not always occur. The central GSF team promote the GSFCH coordinators as being the conductor of change within their respective nursing care homes (Gold Standards Framework Centre CIC 2011). However, if the GSFCH coordinators do not attend the workshops, achieving this is much more difficult. Individual learning about the programme will not have taken place. An alternative solution for individual learning by the GSFCH coordinators was not identified by any of the participants. Instead, there was acknowledgement by all the participants of the challenges that arose when the workshops had been missed (Table 7.10).

Context needs to be taken into account when introducing any change initiative (Kitson et al 1998). The turnover of staff within nursing care homes is known to be high (RCN 2011). If this had been taken into account when introducing the GSFCH programme, a solution to GSFCH coordinators individual learning, if they missed a workshop, could have been proactively managed (perhaps by attending another Regional Training

Centres workshop). It was not addressed at all by any organisation or individual involved in the implementation of the GSFCH programme.

The success of education alone at achieving change, especially the cultural change that the GSFCH programme required, is questionable (Froggatt 2000a/b). Learning consists of more than education. Senge et al (1999:24) supported this finding stating learning occurred: ‘through experience gained by following a track or discipline. Learning always occurs over time and in real life contexts not in classrooms or training sessions’. This approach to learning is supported by others (Fixsen et al 2005 and Showers and Joyce 1996). In this study, in the *high facilitation* groups, learning did occur in the nursing care home, in the real life context that Senge et al (1999) identified. As well as learning through education in the GSFCH workshops, the nursing care home staff also learnt through role modelling. This occurred in the *local facilitation* group, but to a lesser degree (see 7.6.4.4.3).

There is some evidence that supports the value of role modelling to learning. It helps develop craft knowledge – the translation of theory to practice (Perry 2009). An observational study reported this, when medical residents were learning an appropriate bedside manner (Weissmann et al 2006) as did Donaldson and Carter (2005), for nursing students within the clinical area and Showers and Joyce (1996) for teachers in classroom training. An evaluation by McCormack and Slater (2006) within a hospital setting demonstrated that supporting learning of new nurses in the workplace resulted in individual learning but not organisational learning. In relation to the implementation of the GSFCH programme, only one earlier study was found to support its use (Hockley et al 2008). A recent publication highlights that in nursing

care homes, role modelling offers a way of transferring individual learning about end-of-life care into clinical practice (Kenyon 2013). What Kenyon (2013) identified, supported by this study, is that individual learning involves work (as defined in the introduction to this chapter). It was active work alongside the receipt of information that changed practice.

The 'worldview' component in Soft Systems Methodology, enabled the important contribution staff made to transferable knowledge to be recognised (Checkland 1999). Where staff moved between work environments, individual learning was transferrable. Several participants indicated how useful it had been when implementing the GSFCH programme, if staff had an awareness of what the programme was about from their previous work experiences. However, past individual learning needs to be discussed and understanding clarified. Several external facilitators mentioned that GPs who were familiar with the primary care GSF programme assumed they knew everything about the GSFCH programme. They are quite different. Where nursing care home staff had been part of the programme before, they had opinions of the GSFCH programme and these affected their current individual learning (Table 7.6). Once again discussion and clarification was needed.

ii. The external facilitators

The external facilitators, like the GSFCH coordinators also needed to undertake individual learning. Recognition that individual learning was required by the external facilitators was unexpected (see Box 6.1, 6.5.2 and Table 7.2). I had presumed that individuals appointed into the role of a GSFCH external facilitator had experience of undertaking this role before. I assumed they were therefore competent and confident,

about providing it again. I had wrongly made an assumption that the individual learning needed to undertake the role of a GSFCH external facilitator, had already occurred. This was not the case.

Individual learning for the external facilitators did not always occur. Some external facilitators in the *local facilitation* group had attempted but failed to find out how they should undertake the facilitation role that they had been employed to carry out (see Box 6.1). When undertaking their role, these external facilitators worked individually in a nursing care home. The nursing care home staff may have undertaken the programme before, but would not have successfully completed it.

External facilitators were meant to be the expert. However it was clear that this was not always the case. A nursing care home manager in one nursing care home knew more about the programme than her external facilitator (Table 7.2). This may increasingly be the case, unless a process of individual learning for the external facilitators is established. Reflecting back on their experience, the external facilitators viewed the workshops as a means of individual learning for themselves. Joint attendance at GSFCH workshops of the external facilitators with the GSFCH coordinators resulted in joint learning of the programme and joint action planning. The establishment of an action plan was about forward planning, about seeing a vision of where the nursing care home needed to be, looking at where they currently were and documenting how they intended to bridge the gap.

If the external facilitator provided a ‘being present’ approach to facilitation in the nursing care home, joint learning continued to occur, as the action plan devised at the

GSFCH workshop was put into place. The external facilitators described examples of where this occurred and where such experiences had resulted in their individual learning and they changed how they subsequently provided facilitation of the programme: an example being, instead of one coding meeting in a whole nursing care home they instead encouraged them to occur on every floor. In this example, it was only by ‘being present’ that environmental constraints to learning in a specific organisation could be recognised and therefore addressed (Checkland 1999).

The integration of qualitative and quantitative data further demonstrated the value for a ‘being present’ approach to facilitation. This approach resulted in the external facilitators learning with the nursing care home staff that the facilitation role, needed in the consolidation phase of the GSFCH programme, varied from that which they had been asked to provide. The external facilitators, using a ‘being present’ approach, identified that specific support needed to be provided to the nursing care home staff when they applied for accreditation. Whilst this was not part of the approach to facilitation they had been asked to provide ‘being present’ revealed it to be an essential part of their role and so they provided it.

The central GSF team did not meet the individual learning needs of the external facilitators in the *local facilitation* group in this study (see Box 6.1). Since this study was completed, the end-of-life care programme has published a competency guide for facilitators (The National End of Life care programme 2012). However this is not necessarily a competency guide for the facilitation of the GSFCH programme. The external facilitators in this study had asked for basic information about their role in relation to this specific programme, which they had failed to gain. This information is

not available in the published literature. The GSFCH coordinators were given a Good Practice Guide as part of the programme but perhaps there is a need for the external facilitators to have something similar. The external facilitators attached to the Regional Training Centre were given a Good Practice Guide – but this was requested and not routine practice by the GSF central team.

In this study, without a national model to guide facilitation of the GSFCH its provision varied. However, the presence of an external facilitator was not enough to ensure completion of the GSFCH programme. The *local facilitation* nursing care homes only had on average one hour of facilitation support in year two. Yet, this represented half of the total time of the entire GSFCH programme that the nursing care homes had paid to undertake. It is the provision of appropriate facilitation that was key to the successful implementation of the change that this programme requires (Harvey et al 2002). The GSFCH coordinators implementing the GSFCH programme needed individual support to learn their role and the external facilitators require the same. Currently, the opportunity for individual learning by the GSFCH external facilitators about their role or assessment of their competency, is not sufficient.

iii. The nursing care home managers

There was great variety in the individual learning of nursing care home managers. Some nursing care home managers were GSFCH coordinators with one undertaking self learning and then teaching the Macmillan ‘Foundations in Palliative Care for Care Homes’ Training herself.

The nursing care home manager taking a lead in the GSFCH programme is important in bringing about change. The action learning sets in the *high facilitation and action learning* group ensured commitment to the GSFCH programme and that action, as a consequence of their learning in the set, was taken by the nursing care home manager, to aid its implementation (Dzik-Jurasz 2006). This engagement of the nursing care home manager at a critical thinking level contributed to the successful accreditation of the nursing care home. It involved individual learning but at a systems level. This same effect was reported by Hewison et al (2011) when using action learning to improve end-of-life care.

Cultural change requires nursing care home managers to be committed to the change (Stone 2003). When undertaking health systems change, Hendy and Barlow (2011) report that engagement of management at the start of the process was important so they could guide those implementing the change. The provision of action learning to the nursing care home managers in the *high facilitation and action learning* group enabled this to occur. However, it has implications as a model of facilitation within the GSFCH programme with respect to its delivery and cost.

9.2: Organisational Learning

Whilst the initial focus of the GSFCH programme is individual learning by the GSFCH coordinators, the intended outcome of the programme is one of cultural organisational change (Gold Standards Framework Centre CIC 2011). Senge et al (1994) refers to organisations undergoing such change as *learning organisations*. This is reported to take time. Fixsen et al (2005) following a review of the literature on

attempts to implement practices or programmes in any domain reported it took two-four years to implement a programme into a new community.

A great strength of the GSFCH programme lay in its structure of putting systems into place which, if followed, focused on the creation of organisational or systems change (Gold Standards Framework Centre CIC 2011). Achieving such cultural change involved harnessing and embedding the GSFCH coordinators, external facilitators and nursing care home managers' individual learning into practice. It then contributes to change within the nursing care home and the development of a *learning organisation*. Achieving such change, in relation to end-of-life care, in a nursing care home setting is challenging. In the *no local facilitation* group organisational learning was not built on from the GSFCH coordinators individual learning. The core GSFCH components: namely coding meetings, reflective practice, use of tools and specific documentation had not been implemented. To achieve this facilitation would seem to be essential.

The five elements that Senge et al (1994) identify to make up a *learning organisation*: personal mastery, mental models, shared vision, team learning and systems thinking are essential and achieving these in practice requires 'being present' facilitation. If the external facilitator provided an 'as requested' or 'fitting it in' approach to facilitation rather than a 'being present' approach the opportunity for work (translating education into actual practice) did not necessarily arise. The literature review in Chapter Four, in relation to the process of implementing an end-of-life care intervention, identified that knowledge translation into practice did not occur through didactic education alone. This study's findings support this. It also identified that 'being present' was not sufficient for cultural change to occur; the study participants also needed to know

what to do. It could be argued that rather than ‘being present’ facilitation, it was engagement with the GSFCH programme that was the most important aspect. However, whilst engagement was crucial, knowing how to engage, and making a commitment to engage with the implementation of the programme only occurred when care home staff were supported with the ‘being present’ approach to facilitation. This is further discussed by considering the five elements Senge et al (1994) identified in relation to implementation of the GSFCH programme and its facilitation.

9.2.1: Personal mastery

In this study, personal mastery was about having clarity of the current reality within the nursing care home but alongside this, having a personal vision about what a new reality could be like. This vision should provide intrinsic motivation for change. If individual learning achieves this creative tension, cultural change is possible. Work is needed however, to move from the current reality towards the vision. A substantial challenge for the GSFCH coordinators was to enable every member of staff to individually appreciate the value of the programme, before they would engage and contribute to it. Failure to achieve personal mastery by at least one member of the system, whether this was by the GSFCH coordinator, the nursing care home manager or the external facilitator would inhibit further progress.

To have a personal vision, you need to see the current reality. This may explain why a ‘being present’ approach to facilitation resulted in more nursing care homes completing the GSFCH programme. Personal mastery by the external facilitators would not be possible if they had used the ‘as requested’ or ‘fitting it in’ approach to

facilitation. Ongoing knowledge of the current situation would only be possible by 'being present' with the staff in the nursing care home.

9.2.2: Mental models

Individuals all have a personal picture and understanding of the world. They are unique, as every situation that is encountered will be interpreted slightly differently by different individuals (Senge et al 1994). These interpretations, pictures or mental models shape an individual's actions and decisions. They are not static. Over time, mental models are reflected on, tested out, clarified and altered. Senge et al (1994) recognised some mental models or perceptions were deep rooted beliefs; they lay below the level of awareness and so often remained untested. Changing these could only occur with conversations or/and reflection within the system, where such assumptions could be discussed or challenged.

As the GSFCH programme is one that involves cultural change, knowledge of mental models would be essential to achieve such change. Senge et al (1994:267) described an organisation's culture as 'its member's collective mental models which is why you cannot change an organisation without investigating its cultural assumptions.' An awareness of such mental models would only emerge as a consequence of the 'being present' approach to facilitation. It was intended that as the GSFCH programme was implemented, over a two year period, culture would change. External facilitators who continued to 'be present' remained part of this cultural change and so could appropriately contribute to future decisions and actions. The 'being present' approach to facilitation was the only facilitation approach that enabled such ongoing learning by the external facilitator. This view of learning from practice is not new. The concept

was described by Wenger (1999; 95): ‘...one reason they do not think of their job as learning is that what they learn is their practice....what they learn is not a static matter but the very process of being engaged in, and particularly in developing, an ongoing practice.’

A strength of the GSFCH programme was that it recommended putting time aside to reflect on practice. This process could help identify individual’s mental models. However, it was only a strength if it was translated into practice within the nursing care home. In this study, without high *facilitation* and the associated ‘being present’ approach to facilitation this failed to occur.

9.2.3: Shared vision

To become a *learning organisation*, there needed to be a transfer of information from that individually learnt at the workshops by the GSFCH coordinators. Learning needed to become organisational-wide (see 7.6.3). To achieve this there needed to be, what Hendy and Barlow (2011:351) described as, ‘a significant shift in the ownership of the work’. This shift of ownership could only occur, if the organisation could grasp a shared vision of the future. Hendy and Barlow (2011) suggested that internal champions’ strength lies in their ability to do just this. Individual members of the organisation needed to learn. They needed to be able to see what the intended outcome of implementing the GSFCH programme would be and that achieving this was realistic. If individual learning had not occurred for the GSFCH coordinators they would not be able to convey this vision (their mental model). One way to evidence that a collective shared vision had developed was by the nursing care homes successful accreditation. In this study achieving such transformation was more likely

if the nursing care home had a 'being present' external facilitator and the nursing care home manager attended action learning. These activities enabled the external facilitator and the nursing care home manager to become part of the shared vision.

Ongoing work would be needed to sustain this vision. As the situation changed other components of the learning organisation would need realignment. This would include each individual's mental models and personal mastery.

9.2.4: Team learning

Team learning occurred when the members within the team, together have a greater ability and intelligence than the sum of the individual member's parts (Senge et al 1994). To become a learning organisation, the team then need to collectively move forward.

From the Preliminary Phase of the GSFCH programme onwards all the members of the internal system of the participating nursing care homes, needed to learn together. The establishment of the coding meetings, the SEA 'reflective practice' meetings and the creation of the portfolio enabled this process. Such activities also ensured the sharing of personal mental models and the creation of a shared vision. These three elements built one on another. The only nursing care homes to consistently undertake these activities with their staff were those provided with *high facilitation*.

The coding meetings were a place for sharing information about residents, where collective group decisions were made from the shared information. The care for each resident was then planned as a result of the learning that had taken place. Coding

meetings, with associated team learning, took place in all the *high facilitation* groups and some of the *local facilitation* and *no local facilitation* groups.

Significant Event Analysis meetings were only reported to have occurred within the *high facilitation* groups. Where these reflective sessions occurred collective sharing led to increased learning. This took time and effort. They only occurred in the *high facilitation* groups. The external facilitator's role modelled the process. It was then continued by the entire nursing care home and other external health care professionals, who had been invited to join the process.

The GSFCH programme promotes reflective practice as a mechanism for learning. An earlier study reported that the introduction of an adapted LCP into the practice of eight nursing care homes was enabled through the use of reflection. Here collaborative learning groups acted as a forum for reflection after the death of a resident and provided an opportunity for education (Hockley et al 2004). However, there is little evidence within the literature, of the impact on shared learning through reflective practice. The involvement of an external facilitator with this process might. In a literature review looking the benefits of debriefing in relation to learning identified 11 papers. Whilst only one of these had learning outcome data, they reported that the success of debriefing for learning was dependent on the skill of the facilitator (Cant and Cooper 2011). This suggests that a 'being present' approach to facilitation supports team learning. An audit of case review meetings (defined as a retrospective analysis of an episode of patient care) suggested that facilitation of such sessions resulted in deeper and broader learning (Bellamy et al 2006).

Another activity that supported team learning was the creation of the portfolio for accreditation. It captured their individual practice and their shared experiences. It had to tell the story of how the programme was put into place from the start to the end and evidence every comment made. This process was also only possible through the engagement of all team members and learning occurred during its creation. Accreditation represented accreditation of the nursing care home, not individuals. The GSF assessor visit was to ensure cultural transformation had occurred throughout the nursing care home (Thomas et al 2013). This could not be achieved alone. It required team learning not individual learning. It could be postulated that this was achieved through engagement of the care home staff with the implementation of the GSFCH programme rather than through ‘being present’ facilitation. However, in this study, whilst the portfolio could only be created by the engagement of the entire home with the process, the team learning it required better occurred if this process was supported by external *high facilitation*.

Interestingly, one *no local facilitation* nursing care home, despite having no access to an external facilitator, did become accredited. In this nursing care home, team learning occurred through the nursing care home manager taking on an internal facilitator role rather than through external facilitation. The manager acted as the ultimate ‘being present’ facilitator. By running education sessions in the nursing care home for all disciplines of staff and getting them to assist with subsequent education sessions, the staff helped each other and learnt together. This was the only nursing care home to report this occurring. This was also the only nursing care home in the *no local facilitation* group successfully accredited. It required hard work by this nursing care

home manager, who was determined to complete the programme. 'Being present' facilitation was still required. It was internally rather than externally provided.

9.2.5: Systems thinking

The term systems thinking in this thesis, is taken to mean the relationship between the systems main components (Senge et al 1994). It includes recognition of intra-connections (within the system) but also of the inter-connections (from one system to another). Its recognition brings knowledge that what occurs in a nursing care home will effect another external organisation and likewise, what occurs in an external system may influence nursing care homes, within the system.

Challenges to the nursing care home becoming a learning organisation occurred when the GSFCH coordinators failed to engage the rest of their organisation and their external community, with the programme. The nursing care homes were not able to implement the programme without their internal (manager/nursing/care staff, relatives and residents) and external systems (e.g. GP, local palliative care and chemist) both understanding the programme and wanting to engage with it. In both *high facilitation* groups, the external facilitator was instrumental in developing such systems thinking. Time was spent helping the nursing care homes develop partnership working both within the nursing care home and externally. If there was no external facilitator, such change usually failed to occur (see 7.6.4). How participating nursing care homes developed systems thinking was not formally reviewed within the GSFCH programme. The creation of the portfolio for accreditation required submission of evidence of relationships within and between systems. To obtain such evidence would first require such relationships to be established which would have resulted in systems

thinking. Within this study there was a missed opportunity for development of relationships through the creation of a portfolio by 20 nursing care homes. Only 17 of the 37 nursing care homes within this study applied for accreditation and so took part in this process.

It may be that an important consideration when supporting change is not only access to an external facilitator, but access to a facilitator who is external to the specific organisation implementing change. Hendy and Barlow (2011) found that their process of health system change was enabled when there was a champion who, like the GSFCH external facilitators, was not an internal member of staff. This finding has been reported, with possible rationale provided, by others:

'a person whose selection is acceptable to all members of the group, who is substantively neutral, and who has no substantive decision-making authority diagnoses and intervenes to help a group improve how it identifies and solves problems and makes decisions, to increase the groups effectiveness'

(Schwarz 2002:5)

Whilst this model of facilitation was supported by Ross and Roberts (1999), they also had an additional recommendation. They suggested the external facilitator be supported by an internal facilitator who knew the organisations culture when trying to effect group learning and implement change. The GSFCH coordinators were these internal facilitators.

Understanding organisational learning is complex. The five elements identified by Senge et al (1994) help with not only understanding this concept but also with

identification of what aids its occurrence. When implementing the GSFCH programme a learning organisation was unlikely to develop without the assistance of *high facilitation*, usually provided by an external facilitator.

9.3: Systems Learning

The soft systems approach taken in the thesis illuminated an additional concept. Not only did it highlight the importance of systems thinking (the joining together of a nursing care home and its internal and external systems) for organisational learning to occur, it showed this was not enough. Collaboration between such learning organisations, (the joining together of a nursing care home and its internal and external systems with another nursing care home and its internal and external systems) created learning systems. Blackmore (2005: 338) review of the work of Vickers and described the term learning systems:

'By learning system I mean inter-connected subsystems, made up of elements and processes that combine for the purposes of learning. The placement of a boundary around this system depends on both perspective and detailed purpose.'

This suggests a learning boundary is both flexible and movable.

The goal of a learning system is to share joint experiences and create joint learning (Holmqvist 2003). This means that there is potential for learning to occur not only within an individual system (learning organisations) but also across learning organisations. The joining together of nursing care homes by the external facilitator created learning systems and in doing so, increased the learning potential of these

nursing care homes. This occurred in both *high facilitation* groups and some of the *local facilitation* groups.

There is literature promoting systems learning. The term commonly referred to is inter-organisational learning. The models described mainly related to management collaborations (Winkelen 2010) or a teacher /student collaboration (Lane and Lubatkin 1998). Two processes for learning have been identified:

1. intra-organisational - similar to the learning organisation
2. inter-organisational - learning from another organisation. This learning was noted to need translation before it can be implemented into the culture of another learning organisation (Holmqvisk 2003)

Cultural change in most organisations only occurred when prompted by an external stimulus or agent (Alvesson and Sveningsson 2008). This may mean that the establishment and coordination of inter-organisational learning or learning systems may also need an external facilitator. Once again learning took effort. It required work. Work was required by the external facilitator to initiate and then maintain such learning systems. However, work was also required by the staff in the nursing care homes in order to attend them, participate in them, and learn from them. It was their use, not their creation that led to the learning.

The concept of inter-organisational learning, learning from systems that are in a similar situation, was conceived by Geoffrey Vickers (1983) in his book 'Human systems are different.' He wrote: '....the more uniform the experience of members of a society, the more fully they are likely to share their common language and the more

rich it is likely to be.’ (Vickers 1983:42). The establishment and use of learning systems are dependent upon the users’ perception of them. Effort would only be made to maintain links within learning systems that were perceived as worthwhile. The importance is therefore of learning within an appreciative learning system.

9.4: Appreciative Learning Systems

Vickers (1983) used the additional phase ‘appreciative systems’. The term ‘appreciative system’ is used to describe human activity that results from ‘experiencing relationships, trying to maintain satisfactory ones and elude unsatisfactory ones’ (Checkland 2005: 287). Another phrase was maintaining webs of significance (Checkland 2005).

The creation of such an appreciative learning system between the nursing care homes in the *high facilitation* groups resulted in learning. Nursing care homes have subcultures so support at each level of the organisation is important. The appreciative learning systems ensured learning occurred across nursing care homes and by subculture groups within each nursing care home. The appreciative learning systems that were established provided support for the nursing care home managers, as well as groups in, and peers across, the nursing care homes:

- learning occurred side by side for the GSFCH coordinators in the in the Preliminary Phase of the programme system with the Macmillan ‘Foundations in Palliative Care for Care Homes’ Training (see 6.6.1.3 and Table 6.6).
- learning occurred side by side with action learning for the nursing care home managers, in the *high facilitation and action learning group* (see 7.6.2.2.3 and Box 7.1).

- learning occurred between all disciplines across the nursing care homes in the local nursing care home network forums, in the Implementation and Consolidation Phases of the GSFCH programme (see 7.6.4.3, Table 7.10 and Table 8.6).

Establishing such appreciative learning systems at the beginning of a programme was indicated to be important in this research study. This was the way the nursing care homes in the *high facilitation* groups learnt about the GSFCH programme side by side in the Preliminary Phase, not one ahead of another. Where nursing care home managers learnt together, some saw no boundary to this learning. Members contacted each other, supported each other and learnt from each other between the meetings.

External facilitation might be a means of enabling nursing care homes that are learning organisations (and so are undertaking intra-organisational learning) to undertake inter-organisational learning (become appreciative learning organisations). Simultaneous intra and inter-organisational learning can occur and a suggested model is one where organisations choose to be centred around a core organisation that pools resources and competencies to create joint learning (Holmqvist 2003). In this study such learning only occurred when it was mediated through an external facilitator. What was clear is that for inter-organisational learning, a knowledgeable, skilled external facilitator was required to ensure a 'safe' environment was generated so that learning could occur (Winkelen 2010). A skilled external facilitator was important. The external facilitators in the *high facilitation* group all had a SPC background and facilitation was the sole role, and therefore the priority, of their job. What this may also mean is that for change to occur external, not internal, facilitators are needed.

However, these external facilitators need to be local to the nursing care homes who know the external systems.

The establishment of an appreciative learning system amongst the nursing care homes may represent a way for the GSFCH external facilitators to better support them, perhaps by offering an alternative way of ‘being present’ alongside the nursing care home. As experience was gained by the nursing care homes and the external facilitators, they could increasingly learn from each other. Experience of working within the local area of the organisation undergoing change would mean that the external facilitator was able to bring such knowledge to these meetings.

In addition, the external facilitators also need their own learning system. Like the GSFCH coordinators, external facilitators need to have personal mastery and a mental model. Without these, they failed to provide appropriate facilitation. It was only possible when preceded by individual learning and needed to occur before they came into post. Interestingly, membership of an appreciative learning system offers the opportunity for this. Such a learning system enables external facilitators to learn from and support one another. Such a system worked well in both the *high facilitation* groups in this study.

Learning in this setting, alongside other GSFCH external facilitators, could clearly be beneficial. However to learn, they would have to be engaged with the process. The nursing care homes were perhaps motivated to belong to a learning system, because of the accreditation and then the three-yearly re-accreditation process (see 8.3.2). The external facilitators conceivably need a similar motivation. They should be employed

specifically as external facilitators for the GSFCH programme rather than facilitation of the programme being provided by on an 'ad hoc' basis as was the case in the *local facilitation* group. With the emphasis on outcomes, in the current healthcare climate, it is possible that external facilitators will need to evidence successful outcomes from the facilitation, they are funded to provide. There is perhaps a need for external facilitators to collect evidence of such outcomes now.

The Regional Training Centres are commissioned to undertake the GSFCH programme. It may be that part of this commissioning process could incorporate the provision of support for the accreditation and re-accreditation process. They are already committed to offer an accreditation workshop to all participants, in the Consolidation Phase. However, this half day workshop was not found to be significant in relation to the nursing care homes gaining accreditation, but staff in the nursing care home spending specific time on accreditation with their external facilitator was. Future programmes need to acknowledge, provide and fund this.

A structure for the provision of facilitation for all nursing care homes taking part in the GSFCH programme does not currently exist. Membership of a learning system may create this. One option may be to establish these in the GSF Regional Training Centres. As supporting the nursing care homes with facilitation improves the outcome of the programme (accreditation), perhaps part of the fee that the nursing care homes pay to take part in the accreditation process and their subsequent re-accreditation could contribute to the running costs. This may give the GSF central team evidence of outcomes from the Regional Training Centres that they have commissioned. An alternative approach already used by one Regional Training Centre is that the local

Clinical Commissioning Groups fund the external facilitators in return for providing the essential outcome data they require including place of death and the use of end-of-life care tools (Hockley 2012b).

Facilitation of the GSFCH programme is currently variable and so consequently is the learning experience of the individual participants, the nursing care homes and the nursing care homes external system. Variety in the approach to facilitation will persist unless a model of facilitation for the GSFCH programme to be delivered by the external facilitators is constructed. Without this the term facilitation will remain open to interpretation in terms of definition and consequently in terms of provision.

In this study it was identified that the delivery of high quality end-of-life care, within nursing care homes that the Department of Health (2008) recommends requires cultural change through multi-layered learning, not just individual change in practice. Such cultural change resulted in the delivery of quality end-of-life care becoming normalised into everyday practice. Achieving this required facilitation. The level of facilitation that was required reduced in the second year of the programme. In the Preliminary and Implementation Phases of the programme a higher level of facilitation was required than during the Consolidation Phase (Figures 7.1-7.2).

Cultural change in the one *no local facilitation* nursing care home that became accredited was achieved through internal facilitator support. Specific, structured facilitation was still required. If the soft systems CATWOE approach was used to gain a detailed understanding the individual nursing care homes system prior to starting the GSFCH programme, an appropriate model of facilitation for each specific

home was more likely to be achieved. This may for some nursing care homes reveal members of their own staff who could potentially be internal facilitators. The findings within this study suggest that facilitated support, usually externally provided, is essential when implementing end-of-life care cultural change in nursing care homes.

However, the level of facilitation required beyond the two year GSFCH programme remains unknown. The collection of ongoing longitudinal data is now needed to see if end-of-life care following the completion of the GSFCH programme is normalised into every day practice so that it continues without external support. The current literature suggests this is not the case (Holmqvisk 2003). Ongoing external facilitation is needed to guide and encourage learning. Identification of exactly what such a model consists of is essential. This detail, in relation to the outcomes that occur as a consequence, may make the ongoing funding of facilitated support to sustain the cultural change that this programme has initiated desirable and feasible. It may also be that collection of such data reveals that to achieve cultural change that is sustainable change, particularly in areas with a low context, such as nursing care homes, requires more than facilitation. It may be that an alternative approach such as practice development (McCormack et al 1999 and McCormack 2009), active learning (McCormack et al 2009), emancipator practice development (Manley and McCormack 2003) or 'critical' companionship (Titchen 1998) provides a clearer understanding of the roles and responsibilities required to lead cultural change. What is clear is that without external support individual, organisational and systems learning to enable completion of the GSFCH programme rarely occurred.

9.5: My experience of undertaking this study

What systems theory taught me was that when looking at systems change, everyone's view was important including my own. I believed my presence within the study setting would affect the study findings and so needed to be acknowledged. Acknowledging my career background and core values was as important as the views of other members of this system.

Prior to this study, I had worked in palliative care for over 20 years. My research values had been shaped by my prior work experience. Most of my career had been within the National Health Service where outcomes were an essential and expected component of my role. However on a personal, as well as on a professional level, simply demonstrating an outcome had never been enough. It had always been equally as important to have an understanding of the 'process' - how and why an outcome had or had not been achieved. The use of a research design that permitted recognition of these beliefs and allowed acknowledgment of my physical presence in the study settings was essential.

My interest in process (see Chapter one) meant that there was a huge personal benefit in undertaking this study, as it was undertaken alongside a CRCT. The CRCT measured outcomes that arose when implementing the GSFCH programme, using different approaches to facilitation. Whilst it involved considerable data collection, none took account of the process of implementing the GSFCH programme. Having collected outcome data for two years, it was illuminating to look at why and how change had or had not occurred in each of the settings that I had been visiting. Undertaking a mixed methods study enabled this.

Tension did emerge whilst data collecting, because of my previous role. Several entries in my research diary referred to the absence of change in the nursing care home and the conflict I felt between being able to acknowledge this but not influence it:

'.....the good standards of care that were already in existence continue but little progress has been made in relation to any other aspects of the GSFCH programme. They are not and have not started any resident coding meetings.'

[Researcher]

There was a real sense of unease with recognition that the nursing care homes had paid to undertake this programme and were giving time and commitment to help with the research study. In return I was collecting evidence that exposed their failure to change their practice following attendance at the GSFCH programme. Attendance had not led to implementation of the programme. What was surprising was the enthusiasm and commitment shown by all the participants. This was a two year study. All participants were keen to help at the start and were still engaged at the end.

This was the first time I had tried to understand how change occurred. Taking time to understand the current evidence base was very important. Undertaking systematic reviews ensured that account was taken of previous publications; their recommendations and the identified gaps in knowledge. It revealed that facilitation of the programme was reported as important, but that little was known either about how to provide this, nor the consequences of its provision on the outcomes or process of the programmes implementation.

The use of 'Soft Systems Methodology' made me realise that I had made assumptions when I started this study. What I learnt is that it is important to look at a situation fully, prior to implementing change. It enabled the wider system of the nursing care home to be investigated, rather than just measuring the outcomes or process of change within the home. As each part of a system is important to its function, then understanding how all elements of a system functions prior to the implementation of change is essential. As there is no true picture of reality but rather individual interpretation, this included my interpretation, consideration of each of the pieces that make up the whole must occur, before implementation of change. At the start of this study I had been unaware that the external facilitators of the GSFCH programme did not have any specific guidelines, training or assessment to help provide them with the knowledge and skills needed for this role. Consequently they were not all confident and competent in their role.

9.6: Connecting the findings of the CRCT with the mixed methods study

Whilst the CRCT did not reveal a significant association between the level of facilitation provided when implementing the programme and place of death, there was a greater proportional change in the groups receiving *high facilitation* and *high facilitation and action learning* (see Appendix One). What was significant was the association between the type of facilitation provided and the nursing care homes' completion of the GSFCH programme through to accreditation. The findings of the CRCT suggested that completion of the GSFCH programme, through to accreditation, required *high facilitation* and the provision of action learning. The CRCT only measured outcomes. It was the mixed methods study that provided the detail of how the action learning process contributed to this outcome in practice. The mixed

methods study identified that whilst action learning was important, it was in fact only one example of the multi-layered learning needed to implement the programme. Action learning offered the opportunity to learn at an appreciative system level. It was, however, learning not only at this level, but also at an organisational and individual level that was important.

This mixed methods study identified that to translate end-of-life care policy into care home practice, multi-layered learning was required to achieve cultural change. Striving to undertake studies measuring outcomes, without also taking account of and gaining an understanding of the process, runs the risk of missing the detail of the mechanism through which change was actually implemented. Whilst the significance of an outcome makes implementation of change important, it is the detail of the change process that enables cultural change to occur. Understanding this helps others better understand whether the outcomes of a particular study are potentially relevant to other settings or initiatives.

9.7: Layers of learning and other change initiatives in care homes

Given the enormity and complexity of the population identified as both living and dying in care homes (see 2.4.3), it is not unexpected that national and local initiatives have been undertaken to identify and meet both their health and social care needs. The findings of this study, in relation to layers of learning, are considered in relation to the implementation and sustainability of three such initiatives: reducing the prescription of antipsychotic medication; Namaste Care as an alternative for reducing the inappropriate prescribing of antipsychotic medication; and, the management of incontinence.

A national UK policy initiative especially pertinent to the care home population is that of reducing the prescription of antipsychotic medication. In 2007 the All-Party Parliamentary Group on Dementia undertook an inquiry into the prescribing of antipsychotic medication in care homes to residents with dementia (All Party Parliamentary Group on Dementia 2008). The inquiry was instigated because concerns had been raised about the appropriateness and safety of prescribing antipsychotic drugs for these residents. Within its recommendations was the need to reduce the number of prescriptions. Specific recommendations from the All Party Parliamentary Group on Dementia (2008) included:

- dementia training becoming mandatory for all care home staff
- care homes receiving effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, which should involve regular, pro-active visits to the care home
- compulsory regulation and audit of antipsychotic drugs for residents with dementia

These recommendation targeted action at an individual level (mandatory training), at an organisational level (effective external support) and at a systems level (regulation and collection of audit data). However, recommending change through targeting action at all three levels is not the same as learning occurring at all three levels. It was previously identified within this thesis that it was learning at these levels that led to the implementation of cultural change, rather than only targeting change in practice. Support for a multi-layered approach is evident from the literature reporting on implementation of this national initiative.

In relation to individual learning (mandatory training), organisations external to the care homes developed guidelines to enable the transfer of these recommendations into practice (Alzheimer's Society 2011). A report by Care Quality Commission (2014) following inspection of 129 care homes found that in relation to staffs understanding and knowledge of dementia care, variable or poor care, was evident within 27% of care homes. If these care homes had implemented individual or organisational mandatory dementia training, then learning had not been translated into the practice of all staff in what was a very small subset of care homes in the UK. With this change initiative, although guidelines had been produced for individual and/or organisational learning, implementing this in practice had not been supported by an external professional (similar to the GSFCH facilitator). The proactive support of external services to care homes is known to be limited (Kinley et al 2013b).

A systematic review of interventions to reduce the inappropriate prescribing of antipsychotic medication concluded that current guidelines are difficult to implement in practice (Thompson et al 2014). They report similar findings to those in this thesis; that education programmes alone failed to change practice. In relation to reducing the prescription of antipsychotic medication, the Clinical Audit Support Unit reported a 51.8% reduction in the number of people with dementia receiving a prescription of antipsychotic medication from 2008 to 2011. However, only the interventions supported by specialist external professionals (psychiatric or pharmacists) report a statistically significant reduction in prescribing rates. These are findings that relate to organisational learning rather individual GP practice. As in this study, these external professionals visited the care homes. However, unlike this study there was a failure to look at the entire system before deciding how best to meet the policy

recommendation. The focus was on the outcome – reducing inappropriate prescribing. There was no mention of care homes learning from one another in appreciative learning systems. Whilst the policy target was a reduction of prescriptions, a recommendation by Thompson et al (2014) was to look at the availability and feasibility of non-drug alternatives for reducing the inappropriate prescribing of antipsychotic medication to residents in care homes. A failure to look at the care home system prior to implementing this national initiative has resulted in a failure to integrate pre-existing initiatives.

One such pre-existing initiative is the Namaste Care Programme - a non-drug alternative for reducing the inappropriate prescribing of antipsychotic medication. This is a sensory based programme that provides meaningful activity for residents with advanced dementia (Simard 2013). The importance of meaningful activity is widely supported (Care Quality Commission 2014 and the Alzheimer's Society 2011). It developed from practice. Joyce Simard observed what was occurring in practice before thinking through how best to meet the need. It is a cultural change initiative that has emerged from the care setting. It came from a desire to meet this identified need in practice, rather than a policy recommendation made through existing evidence. The Namaste Care Programme is an example of emergent change (Iles 2006). Evidence about its value in practice as a mechanism for reducing behavioural symptoms and occupational disruptiveness came later. This is just beginning to emerge (Stacpoole et al 2014). Recognition of the importance of meaningful activity has also resulted in the production of guidelines (Simard 2013 and Jakob and Collier 2014).

In order to implement Namaste Care, individual and organisational learning are both essential. Implementation of the programme is coordinated by internal champions working within the care home who apply for the position and, following training, are called Namaste Care Workers (Simard 2007 and Simard 2013). As well as the individual learning by the Namaste care workers, implementation of the programme can only take place in practice if the entire home takes part. This relates to the concept of organisational learning identified within this mixed methods study.

The GP response to behavioural problems is reported to be a prescription (Azermai et al 2013). With the emergence of evidence of effectiveness of the Namaste Care programme (Stacpoole et al 2014), the engagement of GPs with the concept of such non-drug alternatives would also seem to be important (Azermai et al (2013)). Both individual and organisational learning are required. The Namaste Care programme is insufficient on its own. To decrease behavioural symptoms, good medical care is also essential (Stacpoole et al 2014). Simard and Volicer (2010) reported that when implemented, the director of nursing supervised it, but it was the consultant who visited every six months to ensure fidelity of the intervention was maintained. Like with implementing the GSFCH programme, internal coordinators were important, as was ongoing support by a professional external to the day to day running of the care home. The literature on the Namaste Care Programme revealed little evidence of appreciative systems learning other than the attendance of the Namaste Care Workers at a one day workshop (Stacpoole et al 2014). Further details were not provided, though implementation of the findings that emerged from this research study includes workshops, a visit to the care home and a follow up workshop (St Christopher's Hospice 2014). The Namaste Care Workers from across the care homes all meet at the

workshops (appreciative learning systems). Information about sustainability of the initiative following the research study and the subsequent workshop approach is unknown.

Finally, this study's findings are considered in relation to the management of incontinence of residents in care homes. Seventy one percent of residents are reported to require assistance in the management of this particular aspect of their personal care (Bowman et al 2004). Of these, all residents had urinary incontinence, with some additionally having faecal incontinence. Several studies have been undertaken addressing how best to manage urinary incontinence, with systematic reviews available summarising their findings (Flanagan et al 2013 and Roe et al 2011). Roe et al (2011) acknowledged that information is now available to guide practice. However, within the studies undertaken, there are specific challenges that were acknowledged to implementing research recommendations into practice in care homes (Schnelle et al 2002). Within the literature the desired outcome had been generated, like the inappropriate prescribing of antipsychotic medication, but without the soft systems approach of trying to understand what is currently occurring in practice beforehand.

With respect to translation of the research findings into practice, individual learning was required. However, managing incontinence, like implementing the Namaste care Programme, required learning across the organisation to gain consent for example for increased institutional costs (Flanagan et al 2013). This study looked at the role of facilitation when implementing the GSFCH programme. Noting the difficulties of translating continence recommendations into practice, a study protocol was written to examine the role of facilitation in this process (Seers et al 2012). The creation of

internal coordinators, as with The Namaste Care programme and GSFCH programme, was crucial to its implementation. Standard facilitation involves a PowerPoint presentation to the care home manager. In this study, two models of facilitation are being evaluated. The first is described as technical (standard facilitation and 12 months of external facilitation support provided through monthly telecommunication to internal coordinators). The second is one of enabling (standard facilitation and 24 months of external facilitation support provided through monthly telecommunication learning groups to internal coordinators with production of a portfolio of evidence). The internal coordinators had protected time, were chosen specifically for and with an interest in the task. Like this mixed methods study which was undertaken alongside, a CRCT Seers et al (2012) study is looking at process as well as outcome data. When the findings are reported it will be interesting to see how these studies compare.

From the definition of end-of-life care used within this thesis, all residents in a care home setting meet this category. It is perhaps then not surprising that the mechanism for learning described within this thesis resonates across to the implementation of different interventions. With respect to layers of learning, the implementation of all three interventions described above required individual learning. However, what led to cultural change was when this occurred in association with organisational learning. One such example was the implementation of the Namaste Care Programme which resulted in the reduction of antipsychotic medication. Understanding the current system ensured that targeting change in practice was appropriate to the setting and utilised what was already in place. Here, whilst not identified as soft systems thinking, it was systems thinking by Joyce Simard that identified what was in place, and what needed to be put into place before introducing the initiative. Stacpoole et al (2014)

then utilised what was known about implementing this programme into practice and built evidence about it. This revealed that strong leadership, adequate staffing, and good nursing care were also important (Stacpoole et al 2014). Knowledge about the implementation of the Namaste Care Programme came from learning about practice in the care home setting and how to develop this to achieve, rather than enforce, an outcome. The systems based approach that Joyce Simard took meant it was introduced well into the setting for which it was intended. Assumptions were not made, time was taken to understand the current system in context, and it was feasible to ground it in the practice of everyone in the home. The reduction of antipsychotic prescribing by one GP was not sufficient to change cultural practice; it just changed their individual practice.

Little attention was given to the role of the facilitator in the process of change. The work by Seers et al (2012) should widen the understanding of this. What varies, though, is that their study takes on a telecommunication role of facilitation, not a face to face role. It was being in the care home, like the approach taken with the Namaste Care Programme by Joyce Simard (Simard 2013) that enabled appropriate facilitation to be provided.

None of the three interventions discussed above specifically focused on the creation of collaborative appreciate learning systems. However, they all lack longitudinal data. There is little mention of sustainability of interventions in practice and it may be that if future studies address this then the value of these to maintain cultural change could be further explored. Sustained cultural change when introducing other interventions

may require all three levels of learning. Further research needs to be undertaken to confirm or refute this proposition.

9.8: Conclusion

There were a number of findings that emerged from this study. Firstly, was the recognition that there is inequality in the provision of facilitated support to nursing care homes (who all pay the same proportionate fee) to undertake this programme. Secondly, and perhaps more importantly, that completion of the programme was influenced by the facilitation that was provided. However, the presence of an external facilitator was insufficient to ensure completion of the programme. Nursing care homes were more likely to complete the programme where the facilitation that was provided was local, structured, proactive and involved 'being present', utilising a range of facilitation activities. The findings highlight the importance of an external facilitator able to provide an appropriate model of facilitation, being integral to the GSFCH programme.

Providing and receiving appropriate facilitation to implement and sustain cultural change (as evidenced by the nursing care home becoming accredited) involved work. Care homes were identified in chapter three as having limited access to end-of-life care training and specialist support, with little evidence of outcomes arising from the end-of-life care that they provided. However, it was also identified that the day to day work within a care home could be based on practice and/or learning. A culture based on learning involved work (Wilson et al 2009). This study supported the importance of a learning based culture of care, but provided further detail revealing the importance of multi-layered learning. It was the provision of education and training in

three ways (individual, organisational and across organisations) that enabled staff in the care home to engage with and implement an end-of-life care cultural change programme. When this was provided alongside 'being present' facilitation, care home staff were able to engage in a manner that enabled learning to occur at each level.

The model of learning that is proposed within this thesis is therefore one of multi-layered learning. Learning needs to occur at an individual, an organisational and at an appreciative systems level. This only occurred when it was mediated through an external facilitator. The provision of such facilitation requires resourcing and support.

Chapter Ten – Conclusion

Nursing care homes are complex organisations. Although the specific focus of the study was the role of facilitation when implementing the GSFCH programme within UK nursing care home practice, the soft systems approach enabled the wider context of the 38 participating nursing care homes to be considered. It ensured an understanding not only of the facilitation the nursing care homes received, but also of their internal and external context with their associated relationships. A summary of the key findings is now provided. After acknowledging the strengths and limitations of this study, its contribution to knowledge and recommendations to policy and practice are given. Finally recommendations are made in relation to future research.

10.1: Study findings

Completing the GSFCH programme required staff in the nursing care homes to be prepared for and to undertake cultural change. To achieve this required not only the provision of a particular format of facilitation but also recognition by the external facilitator that they needed to be part of the change process. The use of Soft Systems Methodology, within the systematic literature review and throughout the study, helped identify that cultural change: required a practice based intervention; needed to be supported by multi-layered learning; and, needed all members of a system to actively take part. The importance of these findings are set against the background of increased, and increasing, numbers of older people living and dying within nursing care homes and the need for nursing care home staff to deliver not only quality care but quality end-of-life care.

10.1.1: Cultural change required practice based support

Within the study 'being present' facilitation enabled the education, provided in the GSFCH workshops, to be translated in context into practice. The external facilitator 'being present' ensured the specific context was taken into account as they worked with the nursing care home staff as they implemented the GSFCH programme into practice. The systematic review revealed evidence of cultural change in practice when education occurred alongside a practice-based intervention such as a link nurse programme, reflective learning groups or multimodal interventions. Change was reported to occur in response to the interplay of context, evidence and facilitation (Kitson et al 1998) and was therefore more likely, when they were taken into account. This only occurred with 'being present' facilitation.

10.1.2: Cultural change needed to be supported by multi-layered learning

Whilst learning on an individual basis was recognised to be important for learning to impact on practice it also had to occur at an organisational and systems level. Where the approach to the facilitation provided was one of '*high facilitation*' all nursing care homes implementing the GSFCH programme learnt at an individual level (workshop attendance), organisational level (the external facilitator went into the nursing care home for coding meetings) and at a systems level (staff in the nursing care home attended a local nursing care home network forum). This was not the case for all nursing care homes in any other group. It was this multi-layered approach that resulted in cultural change, with the completion of the GSFCH programme through to accreditation. Commitment to all three formats of learning only occurred when it was seen to be beneficial and more beneficial than participant's other commitments.

10.1.3: Cultural change needed all members of a system to take part

The external facilitators as well as the GSFCH coordinators and the nursing care home managers all needed to be part of the system that was implementing the change. Participation by all was important for joint learning to occur within the change context. However, implementation of the programme required more than the presence of an external facilitator. Whilst three approaches to facilitation were identified, implementation required a 'being present' approach to facilitation not an 'as requested' or a 'fitting it in' approach. It was not sufficient to just be present. Members needed to be present, with personal mastery of the implementation of the initiative and be willing to work hard to achieve it. Without mastery and commitment, from all participants including the external facilitator, learning and therefore cultural change failed to occur.

10.2: Strengths and limitations of this study

There were a number of strengths and limitations to this study.

10.2.1: Study strengths

There were three main strengths to this study; minimal attrition and the achievement of 100% data collection; the use of a mixed methods design; and that this study paralleled a CRCT.

This study achieved 100% data collection and the only nursing care home to withdraw was one that shut. Achieving this was possible because of the length of the study (two years) and the frequency of participant contact (data was also being collected for the CRCT every month in each nursing care home). These two elements meant time was

available to regularly follow up requests for missing data. Relationships were also established and maintained with each of the participating nursing care homes. The success of this may also perhaps be because I was flexible, always followed things through and ensured I contacted any new participants soon after they came into post. The participants wanted to know more about facilitation and so were committed to the study.

The mixed methods design revealed aspects of the external facilitator's role that within another study design might have remained hidden. The qualitative interview revealed that time was spent helping the nursing care homes with accreditation. This aspect of facilitation was not noticed when the quantitative data was analysed, as analysis focused on the components of the *high facilitation* approach the external facilitators were intended to provide. It was interviewing the external facilitators that identified they were assisting the nursing care homes with accreditation. Whilst not part of the high facilitation approach, the external facilitators had identified this as a need. The use of mixed methods made visible that specific time was spent by the external facilitators helping the nursing care homes with accreditation and encompassed data integration which gave additional insights to the importance of this variable.

A final strength of this mixed methods study was that it paralleled the CRCT. The external facilitators in the *high facilitation* groups knew the facilitation approach they needed to provide as it was a trial. However, this was a real life study and so variety in the delivery of the approach did occur particularly in year two (Table 7.1 and 8.6). The trial also meant that this study examined the role of facilitation in the GSFCH

programme in relation to the delivery of measurable outcomes. The systematic literature reviews undertaken within this study revealed that when looking to implement change, especially in the delivery of end-of-life care, such detail is rarely available. Its relationship to the CRCT ensured that the nursing care home managers signed to take part and so committed to attend action learning. They all attended at least one of these, with 75% attending six or more. Their attendance at the action learning was possibly encouraged as these sets were led by an experienced health care professional. These were an *appreciative learning system* and this study identified that links such as these, when they are seen as beneficial, are sustainable.

10.2.2: Limitations of this study

The limitations to this study included: it parallels a CRCT; the choice of outcomes; the study participants; the methods of data collection; and, the generalisability of the findings.

Whilst this study's linkage to a CRCT was a strength it also meant that the limitations of the CRCT became limitations of this study. The main limitation of the CRCT study was that nursing care homes receiving standard GSFCH facilitation were not randomised. It is therefore possible that factors, other than the provision of facilitation, played a part in their implementation of the GSFCH programme.

Outcomes, the measures chosen to evidence change, acted as a limitation to this study in two ways. Firstly, the study's association with the CRCT meant that the outcomes that this study was measuring the process of implementing were pre-determined by the CRCT. Had they not been pre-determined, additional outcomes from the wider system

may have added value. For example, when funding services commissioners of services in the UK are requesting evidence of a reduction of inappropriate hospital admissions as an outcome of that funding. Measuring the number of all hospital admissions from each nursing care home in the CRCT may have provided greater detail on any cost savings in association with different approaches to facilitation of the GSFCH programme. Evidence of this information may have resulted in increased generalisability of this study's findings. Secondly, within this study, the choice of proxy outcomes as measurements of change means assumptions were made that change had occurred. For example, if coding meetings occurred, it was assumed that team learning had taken place, and if role modelling occurred it was assumed that individual learning had occurred. Whilst this finding was supported by interview data, it was not observed in practice. Proxy accounts were used, rather than observed change in care.

This study did not capture everyone's view. Systems theory acknowledges that everyone's view about a situation under consideration is important. It will be unique and so to gain as full an understanding as possible of a situation, it is intended that everyone's view is sought. The GP, SPC and the resident/family views were not sought. Whilst the views of the members of staff acting as GSFCH coordinators implementing the programme were recorded, the views of all the other nursing care home staff were not.

Data was collected from a number of sources and a variety of formats. However this was all data that was reported to have occurred, not observed to have occurred. Its accuracy relied on the recollection, the recording and the honesty of the participants.

The participants all held senior positions within their organisations and so respect of the wider epistemological concept of seeking truth should, though may not have been, embedded within each of their roles. There may have been unreported data as participating nursing care homes may have sought assistance from unrecorded sources. It is unknown if facilitation was sourced in any other way. Details were not requested, nor provided.

A possible limitation is the generalisability of the study findings to practice. Five nursing care homes participating in this study, failed to find access to any local facilitation. The provision of appropriate facilitation, its format as well as its existence, needs to be resourced. Resourcing facilitation may only be an option if cost can be plotted against savings. The median cost of facilitation of the GSFCH programme in this study can be estimated in relation to the total time of facilitation that was provided (Figures 7.1-7.2). Table 9.1 identifies that cost varied according to the facilitation approach taken. It also identifies the cost for the current mid-band 7 salary (RCN 2014).

Table 9.1: Median cost of facilitation per nursing care home

Facilitation approach	Year 1 median time (hrs)	Year 1 median cost*	Year 2 median time (hrs)	Year 2 median cost**	Total 2yr cost	Total 2014/15 2yr cost
No local facilitation	2	£33.08	1	£16.94	£50.02	£51.24
Local facilitation	17.10	£282.83	7.3	£123.66	£406.92	£416.75
High facilitation	72.58	£1,200.47	50.29	£851.91	£2,052.38	£2,098.62
High facilitation and action learning	105.48	£1,744.64	68.10	£1,153.61	£2,898.25	£2,964.15

*cost estimated from RCN (2009) mid-band 7 salary (minus all other on costs)

** cost estimated from RCN (2010) mid-band 7 salary (minus all other on costs)

Given the current economic climate, sourcing funding for such facilitation could be questionable. However, the generalisability of this study's findings is enhanced when savings are plotted against the cost of facilitation. The CRCT (Kinley et al 2014) running in parallel to this study measured outcomes from implementing the GSFCH programme. It demonstrated a greater proportional reduction in the number of hospital deaths when high facilitation (10% reduction), or high facilitation and action learning (13% reduction) were provided. An admission to hospital of a frail older person that ends in death costs between £2,352 and £3,779 (National End of Life Care Programme 2012). If cost savings are accounted for purely in relation to hospital admission at the end-of-life, then the cost of providing facilitation within nursing care homes for the GSFCH programme could be justified. The cost savings within other care settings could be plotted to see if the current cost of facilitation (Table 9.1) would also be lower than the cost of 10-13% of the hospital deaths currently occurring in the care setting. The GSFCH programme is concerned with reducing inappropriate hospitalisations. The benefits to a specific care setting could be therefore be better

estimated by taking into account the appropriateness of their residents/patients who are admitted to hospital and then subsequently die whilst an inpatient.

10.3: Contribution and recommendations of this study

The use of systems theory and the mixed methods approach to this study has contributed to knowledge and provided policy and practice recommendations, when facilitating the implementation of the GSFCH programme. The contribution of this study and the emerging recommendations are now discussed.

10.3.1: Contribution to knowledge

There is limited evidence supporting the Department of Health recommendation for implementing end-of-life care tools including the GSFCH programme (Department of Health 2008). Studies by Hockley et al (2008), Hockley et al (2010), Clifford et al (2007) and Seymour et al (2009) have evaluated the implementation of the GSFCH programme as a framework to support care in nursing care homes. However, unless there is greater understanding on the implementation processes, this framework is unlikely to result in sustainable change in practice. This mixed methods study adds to this limited evidence base.

This study's findings lend support to the incorporation of practice-based interventions, such as role modelling and significant event analysis, alongside education (the GSFCH workshop based education) when implementing change. The systematic literature review that was undertaken, confirmed the widely held premise that the provision of education contributes to an individual's knowledge but is insufficient to

bring about change. However, what was reported was that when education occurred alongside a practice-based intervention, change was then possible.

From the wide systems approach that this study took, the concept of learning in an appreciative system developed. The GSFCH programme intended that change occurred at many levels in the system, so learning also needed to occur within these levels. Implementation of the programme through to accreditation was most successful when learning occurred not only across, but within, the systems levels (nursing care home manager to nursing care home manager, GSFCH coordinator to GSFCH coordinator and external facilitator to external facilitator). However, it needed to be appreciative as well as multi-level. The identification of this emerged as systems theory incorporates a much fuller picture of a study settings context.

10.3.2: Contribution and recommendations to policy

Implementation of the GSFCH programme is one of several policy recommendations to develop the provision of end-of-life care in nursing care home settings. This study raises questions about the implementation of policy recommendations including the implementation of future end-of-life care tools.

Implementation of any tool or framework, particularly ones that were initially developed for use within other contexts, needs resourcing, guidance and support. Without this, tools can fall into disrepute and/or the intended change fails to occur. In this study, 83% of the nursing care homes that were provided with appropriate facilitation (*high facilitation and action learning*) completed the GSFCH programme through to accreditation. The national average is 13% (Thomas 2012). There is a risk

with this level of accreditation that the programme structure, rather than its implementation, may be seen to be at fault. There are lessons from the LCP report that need to be learnt (Neuberger 2013). Whilst the end-of-life care strategy actively encouraged the implementation of end-of-life care within all care settings, the pace of implementation resulted in policy recommendations that provided little guidance, either about the outcomes that would result from their implementation or how to translate their recommendations into practice. There is perhaps now a need to ensure that implementation of the remaining tools is supported and at a pace that ensures implementation is successful, beneficial and with outcomes that are measurable.

10.3.3: Contribution and recommendations to practice

There are a number of recommendations that this study makes to practice in relation to the implementation and facilitation of the programme for; commissioners; external facilitators, nursing care home managers and the GSFCH coordinators; the Regional Training Centres; and, the central GSF team.

In relation to the commissioners: they have a responsibility to commission the provision of care, including end-of-life care that meets their local population needs. Any services that they commission will have targets that they need to meet. If the commissioners follow the government's policy recommendations, the provision of quality end-of-life care (evidenced by the nursing care home having GSFCH accreditation) then this is more likely to occur with appropriate facilitation. The commissioners need to fund an external facilitator who understands the GSFCH programme and provides them with measurable outcome data on specified targets.

In relation to the external facilitators: they need to have personal mastery of the GSFCH programme before assuming this role. In addition they need to:

- have a work base local to the nursing care home, be present in the nursing care home, and be able to provide a model of facilitation that is structured, proactive and involves ‘being present’ (which includes attending the GSFCH workshops) utilising a range of facilitation activities.
- ensure that learning occurs at individual, organisational and systems levels

In relation to the nursing care home managers: they need to be involved with the implementation of the GSFCH programme in their nursing care home:

- prior to enrolling on the programme, nursing care homes need to fully understand their internal and external support mechanisms for implementing the GSFCH programme. The nursing care home managers need to be provided with information about the support they needed to best implement the GSFCH programme. This would provide an opportunity, prior to committing to start the course, to map out what was currently available to them and to investigate if there was access to any missing forms of recommended support in their locality.
- support is needed at all levels top-bottom in all sub-groups within the nursing care home.
- ensure two staff members (or more) attend all four GSFCH workshops

In relation to the GSFCH coordinators: the GSFCH are the coordinators of change within the nursing care homes. Their presence is vital. Every GSFCH coordinator

needs to nominate a deputy. This would ensure provision was made for the replacement/cover of a GSFCH coordinator if this was needed.

In relation to the Regional Training Centres: they have responsibility for the programme delivery. Their role needs to be expanded:

- They need to provide a mechanism to offer support and guidance to external facilitators.
- In the Preliminary and Implementation Phase, the facilitation of the GSFCH programme should be prescriptive. The Regional Training Centres should use a learning contract with GSFCH coordinators and the external facilitators, with evidence of the progress they have made being brought along to each workshop.
- Regional Training Centres need to aim to develop the nursing care homes attending future programmes into learning organisations. The programme encourages the use of a target sheet in the first GSFCH workshop. This self assessment helps the GSFCH coordinators identify priorities for action. The use of this to assess the links they have within and external to the nursing care home would act as a mechanism for 'systems thinking' that could be referred to again in subsequent workshops.
- Coordination between Regional Training Centres would mean that with negotiation, a new GSFCH coordinator or a GSFCH coordinator who had missed a workshop, could attend one at another venue. They would perhaps need to pay for a minimal fee to cover photocopying and refreshments.

- Regional Training Centres need to encourage and support the development of the nursing care homes and their external facilitators attending future programmes into appreciative learning systems.

In relation to the central GSF team: need to reconsider the role of the Regional Training Centres:

- Currently Regional Training Centres are only commissioned to provide the GSFCH programme. However support for accreditation is needed and so potentially is support for re-accreditation. Discussion with the Regional Training Centres needs to occur re funding for this role. It may be the central GSF Central team give a discount for re-accreditation if a nursing care home helps another with accreditation. This would be possible if there were appreciative learning systems in place.
- If no external facilitator is identified, access should be sourced prior to the nursing care home registering to take part in the GSFCH programme.

10.4: Recommendations for future research

The findings of this mixed methods study recommend that a specific model of facilitation is provided when implementing the GSFCH programme. It also advises the development of multi-layered learning that incorporates *appreciative learning systems* to support the sustainable implementation of the GSFCH. Further research now needs to be undertaken to see if this model:

- works in all care settings or just in nursing care homes
- applies to other cultural change initiatives
- is applicable to other countries

10.5: Concluding comment

Facilitation is integral to the implementation of the GSFCH programme. For the majority of nursing care homes participating in this programme, providing end-of-life care that delivers ‘... *the right care, for the right person, in the right place, at the right time...everytime.*’ (Gold Standards Framework Centre CIC 2012) will only be achievable alongside the provision of appropriate facilitation, before, during and after the programme. The nursing care home implementing this programme need access to and support from ‘the right external facilitator, for the right member/s of the nursing care home staff, for the right nursing care home, at the right time throughout the process.’

References

Abbey J., Froggatt K., Parker D. and Abbey B. (2006) Palliative care in care: a system in change. *International Journal of Older People Nursing* 1(1), 56-63.

Age UK (2013) *Improving later life. Understanding the oldest old*

<http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Improving%20Later%20Life%202%20WEB.pdf?dtrk=true%20> accessed 30/06/13.

All Party Parliamentary Group on Dementia (2008) *Always a last resort: Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes.*

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=322 accessed 05/12/14.

Alvesson M. and Sveningsson S. (2008) *Changing Organizational Culture* Routledge, Oxon.

Alzheimer's Society (2011) *Optimising treatment and care for people with behavioural and psychological symptoms of dementia.*

<http://www.alzheimers.org.uk/bestpracticeguide> accessed 05/12/14.

Anthony P. (1994) *Managing Culture* Open University Press, Buckingham.

Argyris C. and Schön D. (1978) *Organizational Learning: a theory of action perspective* Addison-Wesby Publishing Company, London.

Ashton S., McClelland B., Roe B., Mazhindu D. and Gandy R. (2009) An end-of-life-care initiative for people with dementia *European Journal of Palliative Care* **16**(5), 240-243.

Auvine B., Densmore B., Extrom M., Poole S. and Shanklin M. (2002) What do we mean by facilitation *A Research and Applications Journal* **4**, 53-55.

Azermai M., Vander Stichele R., Van Bortel L., Elseviers M. (2013) Barriers to antipsychotic discontinuation in nursing homes: an exploratory study. *Aging and Mental Health* **18**(3), 346-353.

Badger F., Clifford C., Hewison A. and Thomas K. (2009) An evaluation of the implementation of a programme to improve end-of-life care in nursing care homes. *Palliative Medicine* **23**, 502-511.

Badger F., Plumridge G., Hewison A., Shaw K., Thomas K. and Clifford C. (2012) An evaluation of the impact of the Gold Standards framework on collaboration in end-of-life care in nursing care homes. A qualitative and quantitative evaluation. *International Journal of Nursing Studies* **49**(5), 586-595.

Barnball K. and While A. (1994) Collecting data using a semi-structured interview: a discussion paper. *Journal of Advanced Nursing* **19**, 328-335.

- Barber J. and Thompson S. (2000) Analysis of cost data in randomized trial: an application of the non-parametric bootstrap. *Statistics in Medicine* **19**, 3219-3226.
- Barker K (2014) *A new settlement for health and social care Interim Report*. Kings Fund, London.
- Bate P. (1994) *Strategies for cultural change*. Butterworth – Heinemann, Oxford.
- Bebbington A., Darton R. and Netten A. (2000) *Longitudinal study of elderly people admitted to residential and nursing homes: 42 months on Personal Social Services Research Unit* <http://www.pssru.ac.uk/pdf/p051.pdf> accessed 28/03/10.
- Bellamy A., Fiddian M. and Nixon J. (2006) case reviews: promoting shared learning and collaborative practice. *International Journal of Palliative Nursing* **12**(94), 158-162.
- Belli R. and Callegaro M. (2009) 'The emergence of calendar interviewing. A theoretical and empirical rationale.' 31-52 in Belli R., Stafford F. and Alwin D. (ed) *Calendar and Time Diary Methods in Life Course Research*, SAGE Publications Ltd, London.
- Belli R., Stafford F. and Alwin D. (2009) *Calendar and Time Diary Methods in Life Course Research*, SAGE Publications Ltd, London.
- Benner P. (1984) *From Novice to Expert* Addison-Wesley Publishing Company, California.

Bertalanffy L. (1968) *General Systems Theory. Foundations, Development, Applications*. George Braziller, Inc. USA.

Berta W., Teare G., Gilbert E., Ginsburg L., Lemieux-Charles L., Davis D. and Rappolt S. (2010) Spanning the know-do gap: understanding knowledge application and capacity in care homes. *Social Science & Medicine* **70**, 1326-1334.

Blackmore C. (2005) Learning to appreciate learning systems for environmental decision making: A 'work-in-progress' perspective. *Systems Research* **22**, 329-341.

Borg S. (2001) The research journal: a tool for promoting and understanding researcher development. *Language Teaching Research* **5**(2), 156-177.

Bowling A. (2002) *Research Methods in Health. Investigating health and health services*, 2nd edition, Open University Press, Berkshire.

Bowling A. and Ebrahim S. (2005) *Handbook of Health Research Methods*. Open University Press, Berkshire.

Bowman C., Elford J., Dovey J., Campbell S. and Barrowclough H. (2001) Acute hospital admissions from nursing homes: some may be avoidable. *Postgraduate Medical Journal* **77**, 40-42.

Bowman C., Whistler J. and Ellerby M. (2004) A national census of care home residents. *Age and ageing* **33**(6), 561-566.

Brannan J. (1992) *Mixing Methods: qualitative and quantitative research*. Avebury Publishing Limited, Hants. <http://is2.lse.ac.uk/asp/aspecis/20010012.pdf> accessed 13/08/12.

Braun K. and Zir A. (2005) Using an Interactive Approach to teach Nursing Home Workers about end-of-life care *Assessment of Depression* **7**(5), 280-288.

Broad J., Gott M., Kim H., Boyd M., Chen H. and Connolly M. (2013) Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health* **58**, 257-267.

British Geriatric Society (2011) *Quest for Quality: Joint Working Party Inquiry into the Quality of Healthcare Support for Older People in Care Homes: a call for leadership, partnership and quality improvement*. British Geriatric Society: London. http://www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf accessed 10/05/14.

Burnard P. (2005) Interviewing. *Nurse Researcher* **13**(1), 4-6.

Burnes B. (2003) Managing change and changing managers from ABC to XYZ. *The Journal of Management Development* **22**, 627-642.

Burnes B. (2009) *Managing Change* fifth edition Pearson Education Ltd, Essex.

Burstow P. (2014) *The Commission on Residential Care*

http://www.demos.co.uk/files/Demos_CORC_report.pdf?1409673172 accessed 21/11/14

Calanzani N., Higginson I. and Gomes B. (2013) Current and future needs for hospice care: an evidence-based report <http://www.helpthehospices.org.uk/our-services/commission/resources/?entryid209=132678> accessed 30/06/13.

Campbell D. and Fiske D. (1959) Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychosocial Bulletin* **56**, 81-105.

Campbell H., Hotchkiss R., Bradshaw N. and Porteous M. (1998) Integrated care pathways. *British Medical Journal* **316**, 133-137.

Campbell N., Murray E., Darbyshire J., Emery J., Farmer A., Griffiths F., Guthrie B., Lester H., Wilson P. and Kinmonth A. (2007) Designing and evaluating complex interventions to improve health care. *British Medical Journal* **334**, 455-259.

Cant R. and Cooper S. (2011) The benefits of debriefing as formative feedback in nurse education. *Australian Journal of Advanced Nursing* **29**(1), 37-47.

Care Quality Commission *Headline Statistic Spreadsheet* (2010a)

<http://www.cqc.org.uk/guidanceforprofessionals/socialcare/careproviders/statisticsonregisteredproviders.cfm> accessed 20/03/10.

Care Quality Commission *Guidance about compliance. Essential Standards of quality and Safety* (2010b) http://www.cqc.org.uk/sites/default/files/media/documents/gac_-_dec_2011_update.pdf accessed 17/5/14.

Care Quality Commission *Trends in registered care homes* (2012) Care Quality Commission data requests team/Intelligence Directorate supplied 13/09/12.

Care Quality Commission (2013a) What standards you have a right to expect from the regulation of your care home
http://www.cqc.org.uk/sites/default/files/media/documents/6567_cqc_carehome_a5_amended_web_tag.pdf accessed 17/08/13.

Care Quality Commission (2013b) How we inspect
<http://www.cqc.org.uk/organisations-we-regulate/registered-services/how-we-inspect>
accessed 12/01/14.

Care Quality Commission (2013c) *Information Guide End of Life Care: 800144: Information guide: End of life care v1 00* Personal communication 12/01/14.

Care Quality Commission (2014) *Cracks In The Pathway*
http://www.cqc.org.uk/sites/default/files/20141009_cracks_in_the_pathway_final_0.pdf accessed 05/12/14.

Checkland P. (1999) *Systems Thinking, Systems Practice*. John Wiley & Sons Ltd, West Sussex.

Checkland P. (2005) Webs of Significance: The work of Geoffrey Vickers. *Systems Research* **22**, 285-290.

Checkland P. and Winter M. (2006) Process and content: two ways of using SSM. *Journal of the Operational Research Society* **57**, 1435-1441.

Cheetham N. (2008) Teaching a good death. *Nursing Standard* **23**(2), 62-63.

Clifford C., Badger F., Plumridge G., Hewison A. and Thomas K. (2007) Using the Gold Standards framework in care Homes: An evaluation of the Phase 2 programme. http://www.healthsciences.bham.ac.uk/research/life/GSFCH_report_June_2008.pdf accessed 09/07/10.

Clinical Audit Support Unit (2012) *National Dementia & Antipsychotic Prescribing Audit 2012*, Health and Social Care Information Centre
[http://www.hscic.gov.uk/catalogue/PUB06624/nati-deme-anti-pres-audi-sum-
rep.pdf](http://www.hscic.gov.uk/catalogue/PUB06624/nati-deme-anti-pres-audi-sum-
rep.pdf) accessed 05/12/14.

Commissioning Guidance for Specialist Palliative Care: *Helping to deliver commissioning objectives*, December (2012) Guidance document published collaboratively with the Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK.

<http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf> accessed 10/02/13.

Constantini M. and Lunder U. (2012) OPCARE9 - A European perspective on the last days of life. *European Journal of Palliative Care* **19**(40), 175-177.

Crabtree B. and Miller W. (1999) *Doing Qualitative Research* 2nd Edition Sage Publications Ltd, London.

Crosbie T. (2006) Using activity Diaries: Some Methodological Lessons. *Journal of Research Practice* **2**(1), 1-10.

Crotty M. (2009) *The Foundations of Social Research*. Sage Publications, London.

Curry C., Middleton H. and Brown B. (2009) Palliative Care Training. *Nursing Older People* **21**(9), 18-23.

Dale M., Burnes A., Panter L. and Morris J. (2001) Factors affecting survival of elderly nursing home residents. *International Journal of Geriatric Psychiatry* **16**, 70-76.

Davies S. and J. Seymour (2002). 'Historical and policy contexts' 4-33 in Hockley J. and Clark D. *Palliative Care for Older People in Care Homes*, Open University Press, Buckingham.

Department of Health (2000) 'Care Standards Act (2000)' www.legislation.gov.uk/ukpga/2000/14/section/3 accessed 02/01/13.

Department of Health (2001) *National Service framework for Older People*. Department of Health, London.

Department of Health (2008) *End-of-life care strategy*. Department of Health, London.

Department of Health (2009) *End-of-life care strategy. Quality Markers and measures for end-of-life care*. Department of Health, London.

Department of Health (2012) *End of Life Care Strategy Fourth Annual Report* <http://www.dh.gov.uk/health/files/2012/10/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf> accessed 04/02/13.

Denzin N. (1970) *The Research Act in Sociology*. Butterworth & Co. Ltd, London.

Dewar B. and Sharp C. (2006) Using evidence: how action learning can support individual and organisational learning through action research. *Educational Action Research* **14**(2), 219-237.

Donaldson J. and Carter D. (2005) The value of role modelling; Perceptions of undergraduate and diploma nursing (adult) students. *Nurse Education in Practice* **5**, 353-359.

Dowding C. and Homer P. (2000) Teaching palliative care principles to UK nursing home assistants. *International Journal of Nursing practice* **6**, 160-163.

Duffy A. and Woodland C. (2006) Introducing the Liverpool Care Pathway into nursing homes. *Nursing Older People* **18**(9), 33-36.

Dzik-Jurasz D. (2006) Supporting sustainable change. *Nursing Management* **13**(9), 26-29

Edwards E., Roberts I., Clarke M., DiGuseppi C., Pratap S. And Wentz R. (2002) Increasing response rates to postal questionnaires: systematic review. *British Medical Journal* **324**, 1183-1191.

Edwards P, Roberts I, Clarke M, DiGuseppi C, Wentz R, Kwan I, Cooper R, Felix L, Pratap S. (2009) Methods to increase response to postal and electronic questionnaires. *Cochrane Database of Systematic Reviews* 2009, Issue 3. Art. No.: MR000008.

DOI:10.1002/14651858.MR000008.pub4.

Ellershaw J. (2002) Clinical Pathways for the Care of the Dying: An innovation to Disseminate Clinical Excellence. *Journal of Palliative Medicine* 5(4), 617-621.

Ersek M., Grant M. and Miller Kraybill B. (2005) Enhancing End-of-life care in nursing homes: palliative care educational resource team (PERT) program. *Journal of Palliative Medicine* 8(3), 556-566.

Ersek M., Miller Kraybill B. and Hansen N. (2006) Evaluation of a train the trainer program to enhance hospice and palliative care in nursing homes. *Journal of hospice and Palliative Nursing* 8(1), 42-49.

European Commission (2012) The 2012 Aging Report
http://ec.europa.eu/economy_finance/publications/european_economy/2011/pdf/ee-2011-4_en.pdf accessed 04/01/13.

Evered R. (1980) 'Consequences of and Prospects for Systems Thinking in Organizational Change 5-13 in Cummings T. (ed) *Systems Theory for Organizational Development* John Wiley & Sons, Ltd. Avon.

Farquhar M., Ewing G. and Booth S. (2011) Using mixed methods to develop and evaluate complex interventions in palliative care research. *Palliative Medicine* 25(8), 748-757.

Farquhar M., Preston N., Evans C., Grande G., Short V., Bernalia H., Higginson I. and Todd C. (2013) Mixed Methods Research in the Development and Evaluation of Complex Interventions in palliative and End-of-Life Care: Report on the MORECare Consensus Exercise. *Journal of Palliative Medicine* **16**(12), 1550-1560.

Fielding N. and Fielding J. (1986) *Linking Data*. Newbury Park CA, Sage.

Fixsen D., Naoom S., Blase K., Friedman R. and Wallace F. (2005) *Implementation Research: A Synthesis of the Literature*. University of South Florida
<http://ctndisseminationlibrary.org/PDF/nirnmonograph.pdf> accessed 29/03/14.

Flanagan L., Roe B., Jack B., Shaw C., Williams K., Chung A. and Barrett J. (2014) Factors with the management of incontinence and promotion of continence in older people in care homes. *Journal of Advanced Nursing* **70**(3), 476-496.

Forder J. and Fernandez JL. (2011) *Length of stay in care homes* A report commissioned by Bupa, PSSRU Discussion Paper 2769, Canterbury.

Forder J. and Allan S. (2011) Competition in the English nursing homes market. Personal Social Services Research Unit: University of Kent. Available from:
www.pssru.ac.uk/archive/pdf/dp2820.pdf accessed 26/08/13.

Foss C. and Ellefsen B. (2002) The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of Advanced Nursing* **40**(2), 242-248.

Froggatt K. (2000a) Evaluating a palliative care education project in nursing homes. *International Journal of Palliative Nursing* **6**(3), 140-146.

Froggatt K. (2000b) *Palliative care education in nursing homes* Macmillan Cancer Relief, London.

Froggatt K., Hasnip J. and Smith P. (2000) The challenges of end-of-life care. *Elderly Care* **12**(2), 11-13.

Froggatt K., Wilson D., Justice C., MacAdam M., Leibovici K. and Kinch J et al. (2006) End-of-life care in care settings for older people: a literature review. *International Journal of Older People Nursing* **1**, 45–50.

Froggatt K. and Payne S. (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health and Social care in the Community*, **14**(4), 341-348.

Froggatt K. and Reitinger E. (2013) Palliative Care in Care Settings for Older People
EAPC Taskforce 2010-2012 Report
http://www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/FinalReportCareSettings_Jan22_2013.pdf accessed 30/06/13.

Gibbs G. (1995) Nurses in private nursing homes: a study of their knowledge and attitudes to pain management in palliative care. *Palliative Medicine*, **9**(3): 245-253.

Gold Standards Framework Central Team,

www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/CH%20one%20page%20insert.pdf accessed 19/10/11.

Gold Standards Framework Centre CIC (2011) *The GSF Care Homes Training Programme Good Practice Guide*, National GSF Centre, Shewsbury.

Gold Standards Framework Centre CIC (2012) *Care Homes – The GSF Care Homes Training Programme* <http://www.goldstandardsframework.org.uk/content/uploads/files/GSFCH%20Training%20Programme%20Flyer%20v5%20Final%2026.11.pdf> accessed 30/08/13.

Graham P. (1995) *Mary Parker Follett Prophet of Management* (ed) Beard Books, Washington.

Green J. and Thorogood N. (2005) *Qualitative Methods for Health Research* SAGE Publications, London.

Griffiths R. (1988) *Community care: Agenda for action* Her Majesty's Stationary office, London.

Gubrium F. (1975) *Living and Dying at Murray Manor*, St James Press, London.

Hall S., Kolliakou A., Petkova H., Froggatt K. and Higginson I. (2011a) Interventions for improving palliative care for older people living in nursing care homes. *Cochrane Database of Systematic reviews*. Issue 3. Art. No.: CD007132. DOI: .1002/14651858.CD007132.pub2.

Hall S., Goddard C., Stewart F. and Higginson I. (2011b) Implementing a quality improvement programme in palliative care in care homes: a qualitative study *BMC Geriatrics* **11**(31) <http://www.biomedcentral.com/1471-2318/11/31> accessed 01/01/13.

Handy C. (1999) *Understanding Organisations* fourth edition Penguin Books, London.

Hanson L., Reynolds K., Henderson M. and Pickard C. (2005) A quality improvement intervention to increase palliative care in nursing homes. *Journal of Palliative Medicine* **8**(3), 576-584.

Harvey G., Loftus-Hills A., Titchen A., Kitson A., McCormack B. and Seers K. (2002) Getting evidence into practice: the role and function of facilitation *Journal of Advanced Nursing* **37**(6), 577-588.

Hasson F., Kernohan W., Waldron M., Whitaker E. and McLaughlin D. (2008) The palliative care link nurse role in nursing homes: barriers and facilitators. *Journal of Advanced Nursing* **64**(3), 233-242.

Hayes J. (2010) *The Theory and Practice of Change Management* (3rd edition)

Palgrave Macmillan, Hampshire.

Heals D. (2008) Development and implementation of a palliative care link-nurse programme in care homes. *International Journal of Palliative Nursing* **14**(12), 604-609.

Hendy J. and Barlow J. (2011) The role of the organisational champion in achieving health system change. *Social Science and Medicine* **74**, 348-355.

Heron J. (1989) *The Facilitators Handbook* Kogan Page Ltd, London.

Hewison A., Badger F., Clifford C. and Thomas K. (2009) Delivering 'Gold Standards' in end-of-life care in care homes: a question of teamwork? *Journal of Clinical Nursing* **18**, 1757-1765.

Hewison A., Badger F. and Swan T. (2011) Leading end-of-life care: an action learning set approach in nursing homes. *International Journal of Palliative Nursing* **17**(3), 135-141.

Hicks J. and Allen G. (1999) A Century of Change: trends in UK statistics since 1990. Research Paper 99/111

<http://www.parliament.uk/documents/commons/lib/research/rp99/rp99-111.pdf>

accessed 23/09/12.

Hill T., Ginsburg M., Citko J. and Cadogan M. (2005) Improving end-of-life care in nursing facilities: the Community State Partnership To Improve End-of-Life Care-California. *Journal of Palliative Medicine* **8**(2), 300-312.

Hockley J., Dewar B. and Watson J. (2004) *St Columba's Hospice BRIDGES initiative project. Phase 111. Developing quality end-of-life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life.* St Columba's Hospice, Edinburgh.
<http://www.gmu.ac.uk/copa/publications/documents/ICP%20Executivesummary.pdf>
accessed 29/03/13.

Hockley J., Dewar B. and Watson J. (2005) Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *Journal of research in Nursing* **10**(2), 135-152.

Hockley J (2006) Developing high quality end-of-life care in nursing homes: an action research study. Unpublished thesis: The University of Edinburgh.

Hockley J. and Froggatt K. (2006) The development of palliative care knowledge in care homes for older people: the place of action research. *Palliative Medicine* **20**, 835-843.

Hockley J., Watson J. and Murray S. (2008) *The Midlothian 'Gold Standards Framework in Care Homes' project*

<http://www.healthcareforlondon.nhs.uk/assets/End-of-life-care/Midlothian-GSFCH-project.pdf> accessed 01/02/13.

Hockley J., Watson J., Oxenham D. and Murray S. (2010) The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine* **24**(8), 828-838.

Hockley J. and Froggatt K. (2011) Action research in palliative care: defining an evaluation methodology. *Palliative Medicine* **25**(8), 782-787.

Hockley J., Kinley J. and Stewart R. (2012a) The use of Action Learning Sets to enhance Facilitation of the Gold Standards Framework in Care Homes End-of-Life-Care Programme: the intervention arm of a Cluster Randomised Control Trial. *Journal of Palliative Care* **28**(3), 228.

Hockley J. (2012b) A day in the life of...Jo Hockley, Nurse Consultant. *European Journal of Palliative Care* **19**(3), 141-142.

Hockley J., Levy J., Heal R. and Kinley J. (2013) The use of action learning sets to enhance facilitation of the Gold Standards Framework in Care Homes end of life care programme: the intervention arm of a cluster randomised control trial

http://www.stchristophers.org.uk/sites/default/files/content/38658CH_St_Chris_Jo_Hockley_Poster.pdf accessed 29/03/14.

Hoffman S., Burke A., Helzlsouer K. and Comstock G. (1998) Controlled Trial of the Effect of Length, Incentives, and Follow-up techniques on response to a Mailed Questionnaire. *American Journal of Epidemiology* **148**(10), 1007-1011.

Holloway I. and Wheeler S. (2002) *Qualitative research in nursing*, 2nd edition, Blackwell Science Ltd, Oxford.

Holmqvist M. (2003) A Dynamic Model of Intra-and Interorganisational learning *Organisational Studies* **24**(1), 95-123.

Hughes I. (1996) *How to keep a research diary*.

<http://www.scu.edu.au/schools/gcm/ar/arr/arow/rdiary.html> accessed 25/11/11.

Hughes R. (2009) The strengths and weaknesses of telephone interviews. *European Journal of Palliative Care* **16**(2), 87-89.

Iles V. (2006) *Really Managing Health Care* second edition Open University Press, Berkshire.

Jack B., Gambles M., Murphy D. and Ellershaw J. (2003) Nurses' perception of the Liverpool Care Pathway for the dying patient in the acute hospital setting. *International Journal of Palliative Nursing* **9**(5), 234-240.

Jakob A. and Collier L. (2014) How to make a sensory room for people living with dementia. A guide book.

http://fada.kingston.ac.uk/de/MSE_design_in_dementia_care/doc/How%20to%20make%20a%20Sensory%20Room%20for%20people%20with%20dementia.pdf accessed 05/12/14.

Jick T. (1979) Mixing qualitative and quantitative methods: triangulation in action. *Administrative Science Quarterly* **24**(4), 602-611.

Johnson R., Onwuegbuzi A. and Turner L. (2007) Towards a definition of mixed methods research. *Journal of Mixed Methods Research* **1**(2), 112-133.

Jones A. and Johnstone R. (2004) Reflection on implementing a care pathway for the last days of life in nursing homes in North Wales. *International Journal of Palliative Nursing* **10**(10), 507-509.

Katz J. and Peace S. (2003) *End-of-life care in care homes* Oxford University Press, Oxford.

Keay T., Alexander C., McNally K., Crusse E., Eger R., Hawtin C., Lowitt N. and Ross D. (2000) Adult Education Program in Palliative Care for Nursing Facility Physicians: Design and Pilot Test *Journal of Palliative Medicine* **3**(4), 457-463.

Keay T., Alexander C., McNally K., Crusse E. and Eger R. (2003) Nursing home physician educational intervention improves end-of-life care outcomes. **6**(2), 205-213.

Kenyon B. (2013) Role Modelling GSF principles of end-of-life care to care homes. *End-of-life Journal* **3**(3) <http://endoflifejournal.stchristophers.org.uk/personal-reflections/role-modelling-gsf-principles-of-end-of-life-care-to-care-homes> accessed 27/08/13.

Kelly K., Ersek M., Virani R., Malloy P. and Ferrell B. (2008) End-of-life nursing education consortium geriatric training program: Improving palliative care in community geriatric care settings. *Journal of Gerontological Nursing* **34**(5), 28-35.

Kelly K., Thrane S., Virani R., Malloy P. and Ferrell B. (2011) Expanding palliative care nursing education in California: the ELNEC Geriatric project. *International Journal of Palliative Nursing* **17**(4), 188-194.

Kelley M. (2008) Development of a palliative care education programme in long-term care facilities – response. *Journal of Palliative Care* **24**(1), 60-61.

Kerrison S. and Pollock A. (2001a) Caring for older people in the private sector in England. *British Medical Journal* **323**, 566-569.

Kerrison S. and Pollock A. (2001b) Absent voices compromise the effectiveness of nursing home regulation: a critique of regulatory reform in the UK nursing home industry. *Health and Social Care in the Community* **9**(6), 490-494.

Khan W. (2005) *Holding fast The struggle to create resilient caregiving organisations* Brunner-Routledge , East Sussex.

King N. (2004) 'Using templates in the thematic analysis of text' 256-270 in Cassell C. and Symon G. (ed) *Essential Guide to Qualitative Methods in Organisational Research*, SAGE Publications Ltd, London.

Kinley J., Froggatt K. and Bennett MI. (2013a) The effect of policy on end-of-life care practice within nursing care homes: a systematic review. *Palliative Medicine* 27(3), 209-220.

Kinley J., Hockley J., Stone L., Dewey M., Hansford P., Stewart R., McCrone P., Begum A. and Sykes N. (2013b) The provision of care for residents dying in UK nursing care homes. *Age and Ageing* doi: 10.1093/ageing/aft158
<http://ageing.oxfordjournals.org/content/early/2013/10/15/ageing.aft158.full.pdf+html?hwoaspck=true> accessed 28/02/14.

Kinley J., Dewey M., Stewart R., McCrone P., Stone L., Begum A., Sykes N., Hansford P. and Hockley J. (2014) The effect of different models of facilitation when implementing the Gold Standards Framework in Care Homes programme: A Cluster Randomised Controlled Trial. *Palliative Medicine* 28(9), 1099-1109.

Kitson A., Harvey G. and McCormack B. (1998) Enabling the implementation of evidence based practice: a conceptual framework *Quality in Health Care* 7,149-158.

Knight G. and Jordon C. (2007) All Wales integrated care pathway project for care homes: completing the audit cycle – retrospective baseline audit findings of documented care during the last days of life of residents who died in care homes and the re-audit findings following implementation of the ICP. *Journal of Integrated Care Pathways* **11**(93), 112-119.

Knight G., Jordon C. and Lewis M. (2008) Improving end-of-life care in the care home sector *Practice Development in Health Care* **7**(4), 189-197.

Koloroutis M. (2004) *Relationship-Based Care A model for transforming practice*. Creative Health Care management, Minneapolis.

Kotter J. (2007) Leading Change Why Transformation Efforts Fail
http://cerc.stanford.edu/leading_change.PDF accessed 22/12/12.

Komaromy C. Sidell M. and Katz J. (2000) The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing* **6**(4), 192-200.

Kortes-Miller K., Habjan S., Kelley M. and Fortier M. (2007a) Development of a palliative care education program in rural long-term care facilities. *Journal of Palliative Care* **23**(3), 154-162.

Kortes-Miller K., Habjan S. and Kelley M. (2007b) Palliative care education for long-term care: an evidence-based curriculum development project. *Journal of Palliative Care* **23**(3), 229-230.

Kuhn T. (1996) *The Structure of Scientific Revolutions*, 3rd edition. The University of Chicago Press Ltd, London.

Kuhn D. and Forrest J. (2012) Palliative care for advanced dementia: a pilot project in 2 nursing homes. *American Journal of Alzheimer's Disease & Other Dementias* **27**(1), 33-40.

Laing W. (2012) *Care of the Elderly People: UK Market Survey 2011/12 (twenty-fourth edition)*. Laing & Buisson Publications Ltd, London.

Lane P. and Lubatkin M. (1998) Relative absorptive capacity and interorganisational learning. *Strategic Management Journal* **19**, 461-477.

Lewis P. (1994) *Information-Systems Development*. Pitman Publishers, London.

Lievesley N., Crosby G. and Bowman C. (2011) The changing role of care homes <http://www.cpa.org.uk/information/reviews/changingroleofcarehomes.pdf> accessed 29/06/11.

Macmillan Cancer Relief (2011) *Foundations in Palliative Care* Macmillan Cancer Relief, London. <http://be.macmillan.org.uk/be/p-19455-foundations-in-palliative-care-participant-pack.aspx> accessed 07/03/14.

Manley K. and McCormack (2003) Practice development: purpose, methodology, facilitation and evaluation. *Nursing in Critical Care* **8**(1), 22-29.

Mathews F. and Dening T. (2002) Prevalence of dementia in institutional care *The Lancet* **360**, 225-226.

Mathews K. and Finch J. (2006) Using the Liverpool Care Pathway in a nursing home. *Nursing Times* **102**(37), 34-35.

McClelland B., Ashton S., Roe B., Mazhindu D. and Gandy R. (2008) *End-of-life Care: An evaluation of the implementation of the Gold Standards framework and The Liverpool Care Pathway for people with dementia in five care settings across Greater Manchester. Evaluation Report 2008.*

http://www.ljmu.ac.uk/BLW/BLW_Facultytopleveldocs/EoL_Report.pdf accessed 15/05/13.

McCann M., O'Reilly D. and Cardwell C. (2009) A Census-based longitudinal study of variations in survival amongst residents of nursing and residential homes in Northern Ireland. *Age and Ageing* **38**(6), 711-717.

McCormack B., Manley K., Kitson A., Titchen A. and Harvey G. (1999) Towards practice development – a vision in reality or a reality without a vision? *Journal of Nursing Management* **7**, 255-264.

McCormack B., Kitson A., Harvey G., Rycroft-Malone J., Titchen A. and Seers K. (2002) Getting evidence into practice: the meaning of 'context'. *Journal of Advanced Nursing* **38**(1), 94-104.

McCormack B. and Slater P. (2006) An evaluation of the role of the clinical education facilitator. *Journal of Clinical Nursing* **15**, 135-144.

McCormack B., Dewing J., Breslin L., Coyne-Nevin A., Kennedy K., Manning M., Peelo-Kilroe L. and Tobin C. (2009) Practice development: Realising active learning for sustainable change. *Contemporary Nurse* **32**(1-2), 92-104.

Meijer A., van Campen C. and Kerkstra A. (2000) A comparative study of the financing, provision and quality of care in nursing homes. The approach of four European countries: Belgium, Denmark, Germany and the Netherlands. *Journal of Advanced Nursing* **32**(3), 554-561.

Moebius M. (2002) *Epistemological Triangulation – a Typical Research Approach of the Future?* Henley Management College, Oxon.

Mond J., Rodgers B., Hay P., Owen C. and Beumont P. (2004) Mode of delivery, but not questionnaire length, affect response in an epidemiological study of eating disorder behaviour. *Journal of Clinical Epidemiology* **57**, 1167-1171.

Moran S. (2009) Improving palliative care. *Nursing Management* **16**(2) 14-17.

Moran-Ellis J., Alexander V., Cronin A., Dickenson M., Fielding J., Slaney J. and Thomas H. (2006) Triangulation and integration processes, claims and implications. *Qualitative Research* **6**(1), 45-59.

Moran-Ellis J., Alexander V., Cronin A., Dickenson M., Fielding J., Slaney J. and Thomas H. (2010) Following a thread – an approach to integrating multi-method data sets? www.ccsr.ac.uk/methods/.../Thu/am/.../moranellissummary_000.doc accessed 27/12/11.

Morse J. (2010) 'Procedures and practice of mixed methods design.' 339 - 352 in Tashakkori A. and Teddlie C. (ed) *Sage Handbook of Mixed Methods in Social & Behavioural Research*, SAGE Publications Ltd, London.

Moss Kanter (1995) *Preface* xiii-xix in Graham P. (1995) *Mary Parker Follett Prophet of Management* (ed) Beard Books, Washington.

Munday D., Mahmood K., Dale J. and King N. (2007) Facilitating good practice in primary palliative care: does the Gold Standard Framework enable quality performance? *Family Practice* **24**(5), 486-494.

National Audit Office (2008) *End-of-life Care* http://www.nao.org.uk/publications/0708/end_of_life_care.aspx accessed 25/11/11.

National End of Life Care Programme. *Reviewing end of life care information to inform the QIPP End of Life Care Workstream (2012)*
http://www.thewholesystem.co.uk/wp-content/uploads/2014/07/EoLC_QIPP_Costings_Report.pdf accessed 16/11/14.

National GSF Centre (2014) *The Gold Standards Framework in Care Homes Training Programme Good Practice Guide*. National GSF Centre, Shewsbury.

Neuberger J., Guthrie C., Aaronovitch D., Hameed K., Bonser T., Professor Lord Harries of Pentregarth., Charlesworth-Smith D., Jackson E., Cox D. and Waller S.

(2013) *More Care, Less Pathway A review of the Liverpool Care Pathway*,

Department of Health

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf accessed 28/07/13.

NHS England (2014) *Five Year Forward View* <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> accessed 21/11/14.

Nolan M., Davies S., Brown J., Keady J. and Nolan J. (2004) Beyond 'person-centred' care: a vision for Gerontological nursing. *Journal of Clinical Nursing* **13** (3a), 45-53.

Nolan M., Davies S., Brown J., Wilkinson T., McKee K., Flannery J. and Stasi K. (2008) The role of education and training in achieving change in care homes: a literature review. *Journal of Research in Nursing* **13**(5), 410-433.

O'Cathain A., Murphy E., & Nicholl J. (2008) The quality of mixed methods studies in health services research. *Journal of Health Services Research and Policy*, **13**(2), 92-98.

O’Cathain A. (2010) ‘Assessing the quality of mixed methods research. Towards a comprehensive framework’ 531-555 in Tashakkori A. and Teddlie C. (ed) *Sage Handbook of Mixed Methods in Social & Behavioural Research*, SAGE Publications Ltd, London.

O’Cathain A., Murphy E. and Nicholl J. (2010) Three techniques for integrating data in mixed methods studies. *British Medical Journal* **341**, 1147-1150.

Oddsóttir E. and Sveinsdóttir H. (2011) The content of the work of clinical nurse specialists described by use of daily activity diaries. *Journal of Clinical Nursing* **20**, 1393-1404.

O’Dea G., Kerrison S. and Pollock A. (2000) Access to health care in nursing homes: a survey in one English Health Authority. *Health and Social care in the Community* **8**(3), 180-185.

OECD (2011) *Help Wanted? Providing and paying for long-term care*.
<http://www.oecd.org/els/healthpoliciesanddata/helpwantedprovidingandpayingforcare.htm> accessed 04/01/13.

Ortlipp M. (2008) Keeping and Using Reflective Journals in the Qualitative Research Process. *The Qualitative Report* **13**(4), 695-705.

Owen T., Meyer J., Cornell M., Dudman P., Ferreira Z., Hamilton S., Moore J. and Wallis J. (2012) *My Home Life: promoting quality of life in care homes*
<http://www.irf.org.uk/sites/files/irf/care-home-quality-of-life-full.pdf> accessed 24/12/12.

Padgett D. (2012) *Qualitative and Mixed Methods in Public Health*. SAGE Publications Ltd. California.

Parkes S., Haines C. Foreman D., McKinstry E. and Maxwell T. (2005) Evaluation of an educational program for care nursing assistants. *Journal of the American Directors Association* **6**(1), 61-65.

Partington L., Langhorn H. and Froggatt K. (2008) Educational needs: palliative care link nurses in care homes. *End-of-life Care* **2**(3), 65-70.

Pedler M., Boydell T. and Burgoyne J. (1989) Towards the Learning Company. *Management Education and Development* **20**(1), 1-8.

Penrod J., Cortez T. and Luhrs C. (2007) Use of a report card to implement a network-based palliative care program. *Journal of Palliative Medicine* **10**(4), 858-860.

Perry B. (2009) Role modelling excellence in clinical nursing practice. *Nurse Education in Practice* **9**, 36-44.

Petrova M., Dale J., Munday D., Koistinen J., Agarwal S. and Lall R. (2010) The role and impact of facilitators in primary care: findings from the implementation of the Gold Standards Framework for palliative care. *Family Practice* **27**, 38-47.

Pluye P., Gagnon M.P., Griffiths F, and Johnson-Lafle J. (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies* **46**, 529–546.

Polit D. and Hungler B. (1995) *Nursing Research Principles and Methods*, 5th Edition, J.B Lippincott Company, Philadelphia.

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)
<http://www.prisma-statement.org/index.htm> accessed 24/05/14.

Raines J. and Wight J. (2002) The mortality experiences of people admitted to nursing homes *Journal of Public Health Medicine* **24**(3), 184-189.

Redfern S., Hannan S., Norman I. and Martin F. (2002) Work satisfaction, stress, quality of care and morale of older people in a nursing home. *Health and Social Care in the Community* **10**(6), 512-517.

Reymond L., Israel F. and Charles M. (2011) A residential aged end-of-life care pathway (RAP EoLCP) for Australian aged care facilities. *Australian Health Review* **35**(3), 350-356.

Robinson G. and Gallagher A. (2008) Culture Change Impacts Quality of Life for Nursing Home Residents. *Topics in Clinical Nutrition* **23**(2), 120-130.

Roe B., Flanagan L., Jack B., Shaw C., Williams K., Chung A. and Barrett J. (2011) Systematic review of descriptive studies that investigated associated factors with the management of incontinence in older people in care homes. *International Journal of Older People Nursing* **8**, 29-49.

Ross R. and Roberts C (1999) *Barking and nonbarking dogs* (87-91). In, Senge P., Kleiner A., Roberts C., Ross R., Roth G. and Smith B. (1999) *The Dance of Change* Nicholas Brealey Publishing, London.

Rothera I., Jones R., Harwood R., Avery A. and Waite J. (2002) Survival in a cohort of social service placements in nursing and residential homes; factors associated with life expectancy and mortality *Public health* **116**(3), 160-165.

Royal College of Nursing (2009) *Agenda for Change pay bands 1 April 2009*
http://www.rcn.org.uk/support/pay_and_conditions/pay_rates_2009_-_2010 accessed 16/11/14.

Royal College of Nursing (2010) *NHS Agenda for Change pay scales – 2010/2011*
http://www.rcn.org.uk/_data/assets/pdf_file/0018/233901/003303.pdf accessed 16/11/14.

Royal College of Nursing (2012) Consensus Statement: Liverpool Care Pathway for the Dying Patient (LCP)

http://www.rcn.org.uk/_data/assets/pdf_file/0011/477677/Liverpool_Care_Pathway_consensus_statement.pdf accessed 08/02/13.

Royal College of Nursing (2014) *NHS Agenda for Change pay scales England – 2014/2015*

http://www.rcn.org.uk/_data/assets/pdf_file/0007/572812/nurse-pay-scales-nhs-agenda-for-change-england-2014-2015.pdf accessed 16/11/14.

Rutherford (2012) *Population aging: statistics* House of Commons.

www.parliament.uk/briefing-papers/SN03228.pdf accessed 29/08/12.

Rycroft-Malone J., Seers K., Titchen A., Harvey G., Kitson A. and McCormack B. (2003) What counts as evidence in evidence-based practice? *Journal of Advanced Nursing* 47(1), 81-90.

St Christopher's Hospice (2014) *St Christopher's Hospice Namaste Care Programme Training Package*

http://www.stchristophers.org.uk/sites/default/files/education_flyers/Namaste%20Training%20Programme%20Flyer%202015.pdf accessed 05/12/14.

Sale J., Lohfeld L. and Brazil K. (2002) Revisiting the qualitative-quantitative debate: implications for mixed-methods research. *Quality & Quantity* 36, 43-53.

Schnelle J., Alessi C., Simmons S., Al-Samarrai N., Beck J. and Ouslander J. (2002) Translating Clinical Research into Practice: A Randomised Controlled Trial of Exercise and Incontinence Care with Nursing Home Residents. *Journal of the American Geriatrics Society* **50**, 1476-1483.

Scott T., Mannion R., Davies H. and Marshall M. (2003) Implementing cultural change in health care: theory and practice. *International Journal for Quality in Health Care* **15**(2), 111-118.

Scottish Intercollegiate Guideline Network (SIGN). *SIGN 50: A guideline developers' handbook. Section 6: Forming guideline recommendations*. Edinburgh: Scottish Intercollegiate Guideline Network.

<http://www.sign.ac.uk/pdf/sign50.pdf> accessed 24/05/14.

Schwarz R. (2002) *The Skilled Facilitator* Jossey-Bass, New York.

Sedan J. (2003) 'Managers and their organisations' 105-131 in Henderson J. and Atkinson D. (ed) *Managing care in CONTEXT*, Routledge, London.

Seers K., Cox K., Crichton N., Tudor Edwards R., Eldh A., Estabrooks C., Harvey G., Hawkes C., Kitson A., Linck P., McCarthy G., McCormack B., Mockford C., Rycroft-Malone J., Titchen A. and Wallin L. (2012) FIRE (Facilitating Implementation of Research Evidence): a study protocol. *Implementation Science* **7**(25),

<http://www.implementationscience.com/content/7/1/25> accessed 29/10/12.

Senge P., Kleiner A., Roberts C., Ross R., Roth G. and Smith B. (1994) *The Fifth Discipline Fieldbook* Nicholas Brealey Publishing, London.

Senge P., Kleiner A., Roberts C., Ross R., Roth G. and Smith B. (1999) *The Dance of Change* Nicholas Brealey Publishing, London.

Seymour J. and Froggatt K. (2009) End-of-life care in nursing homes: understanding and mapping innovative solutions. Final report http://eolc.cbcl.co.uk/eolc/files/NHS-EoLC_Care_in_care_homes_report_Jan2009.pdf accessed 14/05/10.

Seymour J., Kumar A. and Froggatt K. (2010) Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine* **25**(2), 125-138.

Shah S., Carey I., Harris T., DeWilde S. Hubbard R., Lewis S. and Cook D. (2010) Identifying the clinical characteristics of older people living in care homes using a novel approach in primary care database *Age and Ageing* **39**(5), 617-623.

Shah S., Carey I., Harris T., DeWilde S. and Cook D. (2013) Mortality in older care home residents in England and Wales *Age and Ageing* **42**(2), 209-215.

Shaw S. (2007) *Nursing Leadership* Blackwell Publishing, Oxford.

Shaw K., Clifford C., Thomas K. and Meehan H. (2010) Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliative Medicine* **24**(3), 317-329.

Showers B. and Joyce B. (1996) The evolution of peer coaching *Educational Leadership* **53** (6), 12–16.

Sidell M., Katz J. and Komaromy C. (1997) *Death and Dying in Residential and Nursing Homes for Older People. Examining the case for palliative care.* Report for the Department of Health. The Open University, Milton Keynes.

Silverman D. (1970) *The Theory of Organisations. A sociological framework* Heinemann, London.

Simard J. (2007) Silent and invisible; nursing home residents with advanced dementia. *The Journal of Nutrition, Health & Aging* **11**(6), 484-488.

Simard J. and Volicer L. (2010) Effects of Namaste Care on Residents Who Do Not Benefit From Usual Activities *American Journal of Alzheimer's Disease & Other Dementias*, **25**(1), 46-50. February 2010.

Simard J. (2013) *The end-of-life Namaste Care programme for people with dementia* Health Professions press, Inc, Maryland.

Singer P. and Bowman K. (2002) Quality end-of-life care: A global perspective. *BioMed Central* <http://www.biomedcentral.com/content/pdf/1472-684X-1-4.pdf> accessed 10/02/13.

Spencer L., Ritchie J. and O'Connor W. (2003) 'Analysis: Practices, Principles and Processes' 199 – 218 in Ritchie J. and Lewis J. (ed) *Qualitative Research Practice*, SAGE Publications Ltd, London.

Stacpoole M., Hockley J., Thompsell A., Simard J. and Ladislav V. (2014) The Namaste Care Programme can reduce behavioural symptoms in care home residents with advanced dementia. *International Journal of Geriatric Psychiatry* doi: 10.1002/gps.4211 <http://onlinelibrary.wiley.com/doi/10.1002/gps.4211/abstract> accessed 05/12/14

Steward R., Hotopf M., Dewey M., Ballard C., Bisla J., Calem M., Fahmy V., Hockley J., Kinley J., Pearce H., Saraf A. and Begum A. (2014) Current prevalence of dementia, depression and behavioural problems in the older adult care home sector: the South East London Care Home Survey. *Age and Ageing* doi: 10.1093/ageing/afu062 <http://ageing.oxfordjournals.org/content/early/2014/05/22/ageing.afu062.short?rss=1> accessed 26/05/14.

Stone R. (2003) Selecting a model or choosing your own culture *Journal of Social Work in Long-term Care* 2(3), 411-422.

Stover R. and Stone W. (1974) Hand delivery of self-administered questionnaires. *Public Opinion Quarterly* **38**(2), 284-287.

Tebbit (2008) *Capacity to Care* The National Council for Palliative Care, London.

The Marie Curie Palliative Care Institute Liverpool, www.mcpcil.org.uk/liverpool-care-pathway/national-international/index.htm accessed 19/10/11.

The Marie Curie Palliative Care Institute Liverpool (2012) *International Liverpool Care Pathway for the Dying Patient (LCP) Programme*
<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/national-international/international/> accessed 08/02/13.

The National End of Life Care Programme (2012) *End of Life Care Facilitator Competency Framework*. <http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/end-of-life-care-facilitator-competency-framework-form.aspx> accessed 02/09/13.

Thomas K. (2003) *Caring for the Dying at Home*. Radcliffe Publishing Limited, Oxon.

Thomas K., Meehan H. and Maryon K. (2005) *The use of the Gold Standards Framework in Care Homes. Report on the introduction of the GSF into 12 Care Homes in the pilot Phase 1 April to December 2004*. National GSFCH Centre.

Thomas K. (2012) *The GSF Care Homes Training Programme* (personal communication). GSF centre: Shrewsbury.

Thomas K., Stobbart-Rowlands M. and Corner H. (2013) *Improving end-of-life care in care homes - developing a national momentum of best practice*

<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Care%20Homes/1.%20GSFCH%20Poster%20-%20Amended%20May%2013.pdf> accessed 28/08/13.

Thompson J., Abbott R., Rogers M., Whear R., Pearson S., Lang I., Cartmell N. and Stein K. (2014) Interventions to Reduce Inappropriate Prescribing of Antipsychotic Medications in People With Dementia Resident in Care Homes: A Systematic Review. *Journal of the American Medical Directors Association* **15**, 706-718.

Tight M. (2002) *Key Concepts in Adult Education and Training*, 2nd edition. RoutledgeFalmer, London.

Thompson S. and Barber J. (2000) How should cost data in pragmatic randomised trials be analysed? *British Medical Journal* **320**, 1197-1200.

Titchen A. (1998) A conceptual framework for facilitating learning in clinical practice RCN/Centre for Professional Education Advancement, Australia.

Vickers G. (1983) *Human Systems are Different* Harper & Row Publishers, London.

- Waldron M., Hasson F., Kernohan W., Whittaker E. and McClaughlin D. (2008) Evaluating education in palliative care with link nurses in nursing homes. *British Journal of Nursing* **17**(17), 78-83.
- Watkins J. and Cooperrider D. (2000) Appreciative inquiry: A transformative paradigm *Journal of the Organization Development Network* **32**, 6-12.
- Watson J., Hockley J. and Dewar B. (2006) Barriers to implementing an integrated care pathway for the last days of life in nursing homes *International Journal of Palliative nursing* **12**(5) 234-240.
- Watson J., Hockley J. and Murray S. (2010) Evaluating effectiveness of the GSFCH and LCP in care homes *End-of-life Care* **4**(3), 42-49.
- Webster C. (1991) The elderly and the early National Health Service. In: Pelling M and Smith R. (Ed.) *Life, Death and the Elderly* pp.165-193.
- Weissmann P., Branch W., Gracey C., Haidet P. and Frankel R. (2006) Role modelling humanistic behaviour: learning bedside manner from the experts. *Academic Medicine* **81**(7), 661-667.
- Wen A., Gatchell G., Tachibana Y., Tin M., Bell C., Kojane J., Zeri K. and Masaki K. (2012) A palliative care educational intervention for frontline nursing home staff: the IMPRESS project. *Journal of Gerontological Nursing* **38**(10), 20-25.

Wenger E. (1999) *Communities of practice: Learning, meaning and Identity*.

Cambridge University Press, Cambridge.

Western S. (2008) *Leadership A Critical Text* SAGE Publications Ltd, London.

Whittaker E., Kernohan W., Hasson F., Howard V. and McLaughlin D. (2006) The palliative care education needs of nursing home staff. *Nurse Education Today* 26(6), 501-10.

Wicke D., Coppin R. and Payne S. (2004) Teamwork in nursing homes. *Journal of Advanced Nursing* 45(2), 197-204.

Williams R. (1993) Culture is Ordinary 5-14 in Gray A. and McGuigan J. (ed) *Studying Culture an introductory reader*, Edward Arnold, London.

Wilson B. (1992) *Systems: Concepts, Methodologies and Applications*. John Wiley & Sons Ltd, New York.

Wilson B. (2001) *Soft Systems Methodology: Conceptual Model Building and Its Contribution*. John Wiley & Sons Ltd West Sussex, UK.

Wilson, C.B., Davies, S., Nolan, M. (2009) Developing personal relationships in care homes: realising the contributions of staff, residents and family members. *Ageing and Society* 29 (7), 1041-1063.

Winkelen C. (2010) Deriving value from inter-organizational learning collaboration.
The Learning Organization **17**(1), 8-23.

World Health Organisation (2004) The Solid Facts Palliative Care

http://www.euro.who.int/_data/assets/pdf_file/0003/98418/E82931.pdf accessed
30/12/12.

World Health Organisation (2012) *Good Health Adds Life To Years*

http://whalibdoc.who.int/hq/2012/WHO_DCO_WHD_2012.2_eng.pdf accessed
04/01/13.

World Health Organisation (2013) Definition of palliative care

<http://www.who.int/cancer/palliative/en/> accessed 10/02/13.

Appendix One: Palliative Medicine paper reporting the Cluster Randomised Controlled Trial

Palliative Medicine

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The effect of using high facilitation when implementing the Gold Standards Framework in Care Homes programme: A cluster randomised controlled trial

Julie Kinley, Louisa Stone, Michael Dewey, Jean Levy, Robert Stewart, Paul McCrone, Nigel Sykes, Penny Hansford, Aysha Begum and Jo Hockley

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
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What is This?

The effect of using high facilitation when implementing the Gold Standards Framework in Care Homes programme: A cluster randomised controlled trial

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Abstract

Background: The provision of quality end-of-life care is increasingly on the national agenda in many countries. In the United Kingdom, the Gold Standards Framework for Care Homes programme has been promoted as a national framework for improving end-of-life care. While its implementation is recommended, there are no national guidelines for facilitators to follow to undertake this role.

Aim: It was hypothesised that action learning alongside high facilitation when implementing the Gold Standards Framework for Care Homes programme will result in a reduced proportion of hospital deaths for residents and improvement in the care home staff ability to facilitate good end-of-life care.

Design: A cluster randomised controlled trial where 24 nursing homes received high facilitation to enable them to implement the Gold Standards Framework for Care Homes programme. The managers of 12 nursing homes additionally took part in action learning sets. A third group (14 nursing homes) received the 'standard' Gold Standards Framework for Care Homes facilitation available in their locality.

Setting/participants: In total, 38 nursing homes providing care for frail older people, their deceased residents and their nurse managers.

Results: A greater proportion of residents died in those nursing homes receiving high facilitation and action learning but not significantly so. There was a significant association between the level of facilitation and nursing homes completing the Gold Standards Framework for Care Homes programme through to accreditation. Year-on-year change occurred across all outcome measures.

Conclusion: There is a danger that without national guidelines, facilitation of the Gold Standards Framework for Care Homes programme will vary and consequently so will its implementation. The nurse manager of a care home must be actively engaged when implementing the Gold Standards Framework for Care Homes programme.

Keywords

Gold Standards Framework in Care Homes, end-of-life care, nursing homes, facilitation, cluster randomised controlled trial

What is already known about the topic?

- The Gold Standards Framework for Care Homes (GSFCH) programme provides a framework for improving end-of-life care provision in care homes.
- Facilitation of the programme is recommended.
- The format of such facilitation is not specified.

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What this paper adds?

- Completion of the GSFCH programme was significantly associated with the level of facilitation provided.
- Nurse managers' participation in the implementation of the GSFCH programme is essential.
- Completion of the GSFCH programme, through to accreditation, is more likely when nurse managers are engaged with implementation of the GSFCH programme at a critical thinking level.

Implications for practice, theory or policy

- National guidelines for facilitation of the GSFCH programme are needed.
- Facilitation requires funding when implementing end-of-life care frameworks.
- The nurse manager of a care home must be actively engaged.

Background

The global population is both ageing and increasing, and so, care of older frail people is one of international concern.¹ The prevalence of frailty is known to increase with age,² and so, an increasing ageing global population will potentially lead to increased demands for long-term health and social care. In the United Kingdom, 15.8% people, aged 85 years and over, live in a long-stay hospital setting or a care home.³ End-of-life care is currently delivered in care homes in England: 19% all deaths occur at a care home,⁴ with 56% of residents dying within a year of admission.⁵

Publication of the End-of-Life Care Strategy⁶ puts the provision of not only end-of-life care but also 'quality end-of-life care' in care homes onto the national agenda recommending the implementation of end-of-life care frameworks and tools to help guide care. The Gold Standards Framework (GSF) was one such framework. The GSF programme, initially used in primary care to help general practitioners (GPs) improve care for people in the last years of life,⁷ underwent considerable adaptation and refinement in order to become a programme for care homes (Gold Standards Framework for Care Homes (GSFCH)). It was intended to be implemented in care homes with 24-h nursing care and care homes providing only personal care. While developed and promoted in England, the GSF team has now developed a policy to enable international implementation of the programme. The GSFCH programme is run yearly with a new phase of the programme starting each year.

The GSFCH has three major aims: to improve the quality of care for people nearing the end of their lives, to improve collaboration with primary care and palliative care specialists and to reduce inappropriate hospitalisation/deaths. The programme consists of three stages: 'awareness raising' (3–6 months), implementation of the programme where principles of palliative care are cascaded down to staff following attendance of key coordinators at four workshops (9 months) and a consolidation stage to embed principles prior to accreditation (9–12 months).

GSFCH accreditation (submission of a portfolio and an assessment visit) demonstrates that a care home has been

externally assessed to have implemented the GSFCH programme into practice and reached a certain standard of quality end-of-life care. However, many homes fail to submit a portfolio of evidence and subsequently do not become accredited.

The interest and uptake of the GSFCH programme led the GSF central team to commission a regional training centre at St Christopher's Hospice with the subsequent formation of the Care Home Project Team in 2008. The team consists of a nurse consultant (J.H.), a research nurse (J.K.), a research assistant (L.S.) and several GSFCH facilitators. The GSF central team recommends that care homes undertaking the GSFCH programme have access to a local facilitator in order to help implement the programme.⁸ However, they neither specify the qualifications of the facilitator nor the format such a role should take.

There is increasing evidence that the synergy between the level of evidence to be implemented in practice, the degree of facilitation and the context within which the development is to occur is important to how well the development is implemented/sustained.^{9,10} Implementing change in care homes requires 'high' facilitation because of the low context of most care homes, that is, the majority of staff are not nurses, and care homes in the United Kingdom lack multi-professional in-house teams.¹¹

Previous studies have shown that facilitation of the GSFCH programme is important.¹² However, local GSFCH facilitators are not employed by the GSF central team and so no facilitative model has been enforced. As a result, the provision of facilitation varies. Where high facilitation (HF) has been provided, results have been encouraging. A study^{13,14} implementing the GSFCH and the Liverpool Care Pathway (LCP) into seven nursing homes using what the authors called HF managed to reduce hospital deaths by 50%. The HF included visiting each nursing home every 10–14 days helping to implement different systems and role modelling good palliative care as the opportunity arose. The authors recommended that an HF model was used when implementing change in a

nursing home context. A further study¹⁵ used action learning as part of the facilitation to improve the critical reflection on issues of concern¹⁶ when implementing an integrated care pathway (ICP) for the last days of life. In this study, nurse managers attended action learning every month. They were given time to present a difficult situation in relation to the implementation that they wanted help to think through. Other members of the action learning set provided 'high challenge' (questioning) and 'high support'.¹⁶ Further work is needed to assess the optimum facilitation required for successful implementation of end-of-life care frameworks/tools; providing HF that incorporates action learning may be important.

This article reports initial findings of a cluster randomised controlled trial (CRCT) to examine the impact of providing HF when implementing the GSFCH programme. Other results including a more in-depth reporting on action learning, bereaved relative feedback, staff questionnaires and use of services by residents are to be reported separately.

Method

The study was carried out over a 3-year period in 38 nursing homes all of whom were participating in Phase 6, GSFCH programme (2009–2011). To be included, the nursing home had to:

- be registered as a care home with nursing providing care for frail older residents;
- have a manager willing to participate in 9-monthly action learning sets (the intervention);
- be based in one of the five Clinical Commissioning Groups local to the regional training centre (so that a specific facilitation model could be provided). Clinical Commissioning Groups are National Health Service (NHS) organisations set up by the Health and Social Care Act 2012 to organise the delivery of NIIS services in England.

In total, 24 local nursing homes met the inclusion criteria and were randomised into two groups. All 24 nursing homes received IIF of the programme (see Box 1) with half of the home managers receiving action learning. A CRCT represented the best design as the intervention could not be implemented to individuals without contamination occurring within the cluster. It was hypothesised that *action learning alongside HF when implementing the GSFCH programme will result in a reduced proportion of hospital deaths for residents and improvement in the care home staff ability to facilitate good end-of-life care (evidenced by their use of end-of-life care tools)*. The consent form was signed by the nursing home manager, the deputy manager and the owner or the regional manager of the nursing care home.

Box 1. The components of 'high' facilitation.

The preliminary stage (June 2008–August 2009):

- The appointment of two coordinators from each nursing home (large nursing homes appointed additional coordinator/s);
- 4-day training for local coordinators by facilitator using the Macmillan 'Foundations in Palliative Care for Care Homes';
- Facilitator support in awareness raising both internally and externally to the nursing home.

The implementation stage (September 2009–May 2010):

- Facilitator visited nursing homes two to three times a month (± 1 contact) along with attendance at four Gold Standards Framework for Care Homes (GSFCH) workshops;
- Facilitator helped coordinators to implement the Liverpool Care Pathway (LCP)/integrated care pathway (ICP) or minimum protocol.

The consolidation stage (June 2010–May 2011):

- Facilitator support to join a local nursing home sustainability cluster group providing the following:
 - Induction days every 6 months for all new staff;
 - On-going training for nurses/carers using the Macmillan 'Foundations in Palliative Care for Care Homes' training;
 - Further role modelling in the nursing home for complex situations by Clinical Nurse Specialist/GSFCH facilitator.

The 14 nursing homes, which did not meet the inclusion criteria, formed an observational group and received standard facilitation of the programme available in their locality. The observational group and the two HF groups attended the GSFCH workshops on separate days.

The daily records of the last 6 months of life/length of stay (whichever was shorter) were read and data extracted, for all residents who had died from 1 June 2008 to 31 May 2011. Two researchers extracted data independently having

previously agreed criteria. On completion of the action learning, the participating nurse managers discussed their experience within a focus group. Consort reporting guidelines were followed.

Sample and randomisation

The trial sample size was calculated on the basis that the average nursing home contained 30 beds and that within

any one year a third of these residents would die giving a sample size of 10 per home. With 12 nursing homes per arm, this would give us more than 80% power to detect a difference between the assumed control proportion of 0.2 and 0.08 in the intervention arm (if we assume an intra-cluster correlation of 0.005) or 0.06 (assuming an intra-cluster correlation of 0.05).

The unit of randomisation was the nursing home. Prior to electronic randomisation by an external organisation, the 24 nursing homes were stratified according to their geographical location in order to account for any variety in end-of-life care provision. All members of the research team except J.H. (who led the intervention) were blind to the randomisation.

Intervention

Two trial arms, each consisting of 12 nursing homes, were established.

Arm 1 – high facilitation and action learning (HFAL)

- In total, 12 nursing homes received HF of the GSFCH programme with nurse managers attending action learning.

Arm 2 HF

- In total, 12 nursing homes received HF of the GSFCH programme only.

In this study, action learning centred on 'leadership' in relation to implementing the GSFCH programme. The 12 nurse managers were divided into two action learning sets. Each nurse manager was asked to attend one 3-h action learning set every month between the first and fourth GSFCH workshops (9 months).

Outcome measures

The primary outcome measure consisted of place of death of resident. Secondary outcomes examined evidence of the following end-of-life care tools: undertaking advance care planning (ACP), having a cardiopulmonary resuscitation decision and using end-of-life care plan documentation (i.e. an integrated care plan for the last days of life (ICP) or minimum protocol (MP)).

Qualitative data regarding the problems that the nurse managers brought to action learning were collected during each set and fed back prior to the next session to nurse managers taking part. A focus group was held following 9 months of action learning. The accreditation status of the nursing home was also recorded at the end of the study.

Analysis

Descriptive statistics were calculated using means and proportions. The primary trial outcome and the secondary outcomes were analysed with logistic regression using generalised estimating equations to account for clustering by nursing home and an exchangeable working correlation matrix. The explanatory variables are as follows.

- Treatment arm: HF versus HFAL.
- Year of study: with three levels (2008–2009, 2009–2010 and 2010–2011).

Because the intervention did not start until the beginning of the second year, the effect of the intervention is reflected in an interaction between treatment and year. The results from the regression are presented as odds ratios with 95% confidence intervals. The trial arms were then combined and the same analysis was undertaken comparing the combined trial arm with the outcomes emerging from the 14 nursing homes in the observational group. The accreditation status of the nursing home is measured at the level of the nursing home, but all other outcomes presented here are measured at the level of the resident. Thematic analysis was used to analyse the qualitative data.

Ethics

Ethics approval was granted by the Joint University College London/University College London Hospitals (UCL/UCLH) Committees on the Ethics of Human Research in 2009. REC reference number: 09/H0715/74.

Results

The median numbers of residents per nursing home were as follows: in the HFAL arm – 61 residents (quartiles 34–83), HF arm – 48 residents (with quartiles 28–59) and in the observational group – 54 residents (quartiles 37–75). One nursing home in the HF arm closed during the study period and, in accordance with the principles of intention to treat, is included for the time it provided data. All other nursing homes remained in the study for the full 3 years (see Figure 1).

The notes of 2444 deceased residents were examined. This accounted for 703 residents' deaths (29%) in the HFAL arm, 805 residents' deaths (33%) in the HF arm and 936 residents' deaths (38%) in the observational group. Demographic characteristics of the residents were unremarkable (see Table 1).

In the HFAL arm, eight nurse managers (75%) attended six or more of the action learning sets. The focus group revealed that prior to the study, the majority of nurse managers had not heard of action learning but by the end had

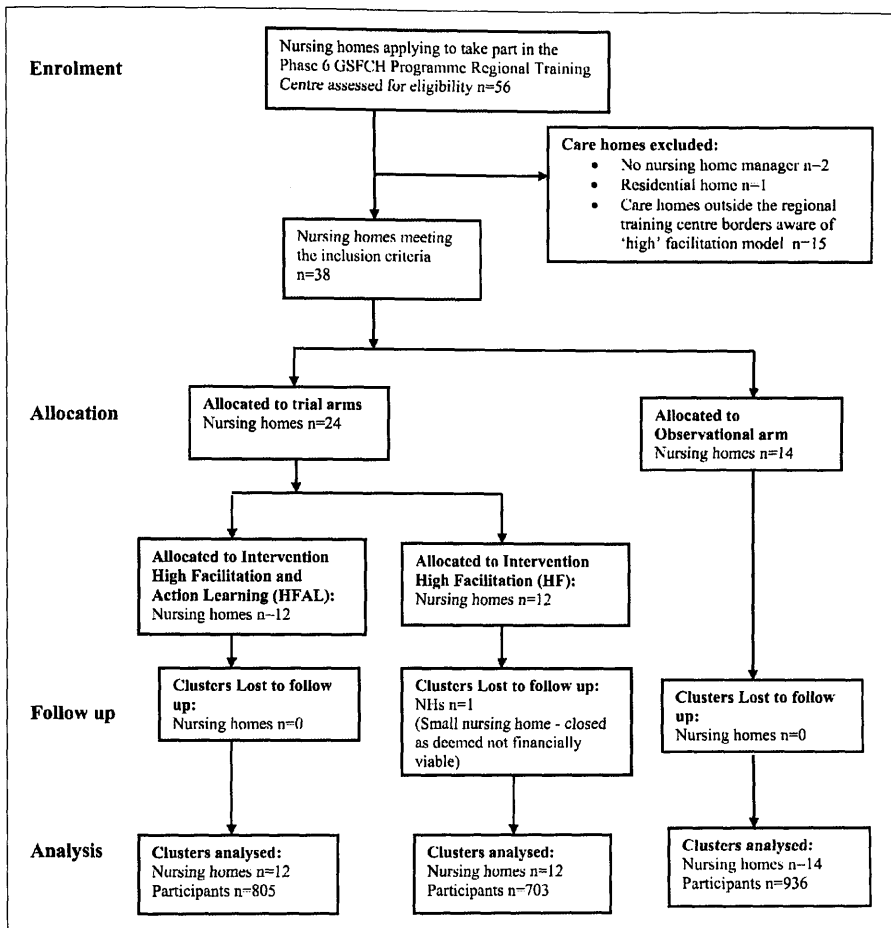


Figure 1. Consort diagram of recruitment. GSFCH: Gold Standards Framework for Care Homes.

wanted the action learning sets to continue. There were five issues that nurse managers frequently presented which included the following: complex residents and challenging families; relationships with GPs and issues to do with 'do not attempt cardiopulmonary resuscitation'; inappropriate hospital admissions/poor communication; time pressures, workload, shortage of staff; and managerial pressures and organisational issues.¹⁷

Analyses of the primary (place of death) and secondary (use of end-of-life care tools) outcomes are shown in Graphs 1–4 and Tables 2 and 3. Given the design, our hypothesis is reflected in the interaction, and values of the odds ratio greater than 1 reflect an increase for action learning for that year over and above the effect of action

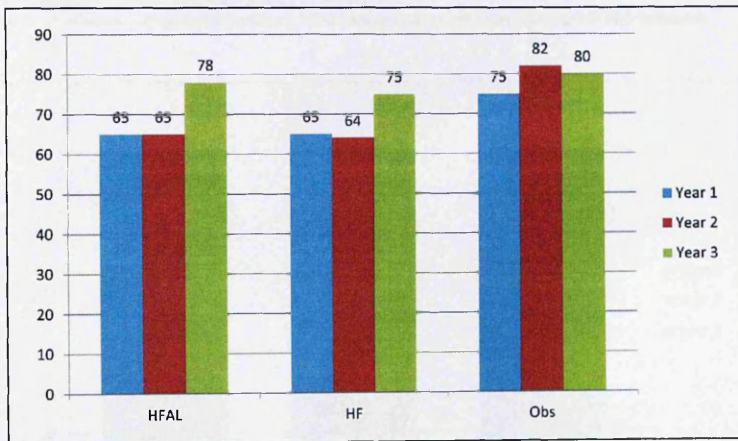
learning and year. The primary outcome reveals no significant effect although the difference by Year 3 was in the expected direction. However, there was a significant effect in the HFAL of one of the secondary outcomes, namely, the use of ICP. The width of the confidence intervals reflects the fact that in the reference category there were very few positives in Year 1. Removing those residents who had died suddenly or died in hospital (and therefore did not have the ICP documentation) and repeating the analyses gave results that were essentially unchanged (results not shown). The other two secondary outcomes revealed no significant effect of the intervention, but in all three, the effect of time was always monotonically increasing.

Table 1. Resident's characteristics.

Resident	Trial arms		Observational group
	High facilitation and action learning	High facilitation	
Gender (female)	58% (463/804)	65% (459/703)	62% (578/936)
Age at death (years)			
Median	86	86	87
Range	33–103	36–105	37–107
Length of stay (days)			
Median	250	260	260
Quartiles	53–877	53–856	46–902
Number of systems affected ^a			
Median	4	4	4
Quartiles	3–5	3–5	3–5
Diagnosis of dementia mentioned in notes	44% (345/799 ^b)	47% (318/682 ^b)	50% (456/919 ^b)

^aResidents' medical diagnosis was categorised into the system of the body that it affected (maximum of 16 possible).

^bThe diagnosis of dementia is unrecorded where the records recording a resident's medical diagnosis were missing.

**Graph 1.** Place of death – nursing home (%).

HFAL: high facilitation and action learning; HF: high facilitation.

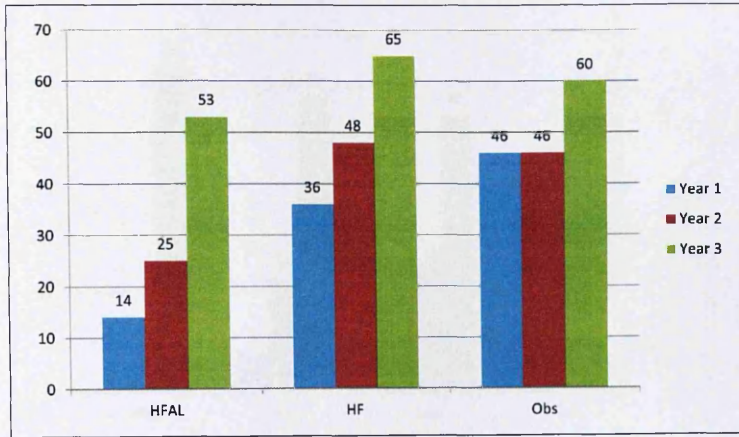
There was also a significant association between the type of facilitation and the nursing homes completing the GSFCH programme through to accreditation. Within the HFAL trial arm, 83% ($n = 10/12$) achieved GSFCH accreditation compared to 27% ($n = 3/11$) in the HF arm (Fisher's exact test, $p = 0.012$). Within the observational group, 7% ($n = 1/11$) were externally accredited to have successfully implemented and embedded the GSFCH programme into practice compared to 57% ($n = 13/23$) in the combined trial arms (Fisher's exact test, $p = 0.005$).

Discussion

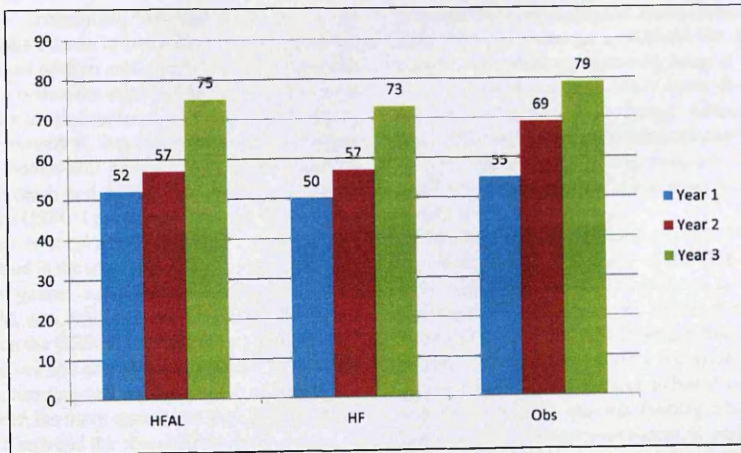
Previous evaluations of the GSFCH programme support clear benefits to facilitating its implementation.^{12,13}

The provision of HF to support care homes implementing the GSFCH programme has been previously reported;^{13,14} however, this is the first CRCT study comparing HF with the addition of action learning as a way of facilitating stronger leadership from a top-down approach.

While the provision of a model of HF in this study did not result in a statistical difference in the primary outcome (place of death), there was a greater proportional change between Year 1 and Year 3 compared to the observational group: HFAL (13%), HF (10%) and observational group (5%). Interestingly, transfer to hospital of frail older people in the last month of life during 'out of hours' with the subsequent result of the resident dying in hospital is not uncommon.¹⁸ While the GSFCH programme alerts staff to the importance of communication with external professionals,



Graph 2. CPR resuscitation decision in place – signed by a GP (%).
 CPR: cardiopulmonary resuscitation; GP: general practitioner; HFAL: high facilitation and action learning; HF: high facilitation.



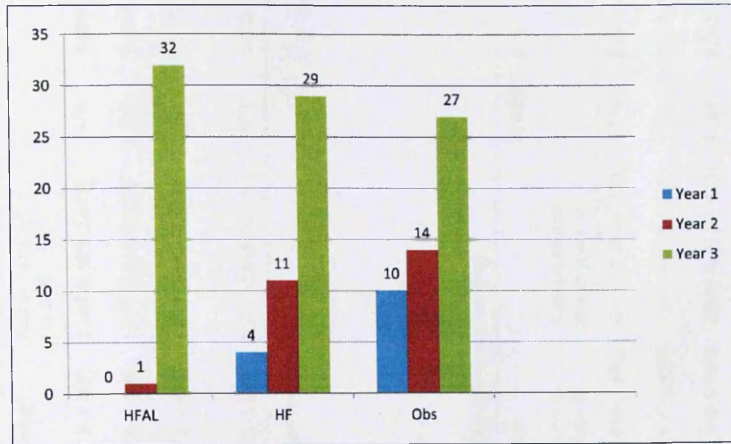
Graph 3. Completed advance care plan (%).
 HFAL: high facilitation and action learning; HF: high facilitation.

many 'out-of-hours' services in our experience have a tendency to admit a frail older person to hospital rather than help advise about end-of-life care. This urgently requires more research in collaboration with out-of-hours services.

In this study, where leadership in end-of-life care was actively discussed through action learning, there was greater proportional change in all outcomes other than ACP. Despite an increase in residents dying in care homes, the difficulties of talking about death and dying and communication among staff are a recurring theme in many care home studies^{19,20} and also in our study. The teaching of

communication skills is important, but unless there is good role modelling and opportunity to practice such discussions, ACP will remain problematic in care homes²¹ because the majority of staff are not trained nurses.

In our study, recognising dying and the use of an ICP for the last days of life showed significantly different results in the HFAL arm ($p = 0.036$). This is likely to be due to the specific support provided to nurse managers through action learning and the open discussions about death and dying that occurred in the majority of the sets.¹⁷ Certainly, this was the case in Hewison et al.'s²² study.



Graph 4. Use of end-of-life care plan (%).
HFAL: high facilitation and action learning; HF: high facilitation.

The GSFCH programme, although highlighting the need for managers/owners to be readily involved, nonetheless does not insist on their active participation. Managers/owners may not realise the extent of the necessary support for staff in order for change to occur. However, the action learning sets ensured it was a manager who attended. Many nursing homes still have a closed communication culture around death and dying¹¹ which prevents implementation of the GSFCH programme through to accreditation unless there is considerable 'top-down' support. This was demonstrated in the observational arm where only one nursing home gained accreditation compared to 83% (10/12) in HFAL arm. Although over 2500 UK care homes have undertaken the GSFCH programme, to date less than 13% have received the accreditation award.²³ It appeared that the action learning sets engaged nurse managers at a higher level from the more casual role held by nurse managers of the HF arm and the observational arm.

Attendance of the nurse managers at the 9-month action learning sets was high. Having the nurse managers sign consent as part of the research may have encouraged greater commitment and therefore better attendance than an open-ended arrangement common to other action learning sets. Commitment to such a group for nurse managers who already appear to have multiple roles is challenging. It could be argued that having members of action learning sets sign up to attend over a defined period might encourage attendance. Interestingly, a study where nurse managers attended action learning on a bi-monthly basis and were given incentives (backfill plus travelling expenses) had lower attendance than our study.²²

Despite nursing home organisations being in competition with each other,²⁴ the action learning sets fostered

networks and relationships at management level across the NHs. The sets provided a platform for the managers to support each other and critically look at their own practice.²⁵ Different managers learnt about different problems that other managers were facing. Action learning challenged the 'taken for granted assumptions' which are often invisible when trying to change practice.¹⁶ This final factor could have been a further incentive for managers to attend regularly.

This study has highlighted a couple of aspects important to the actual facilitation of the GSFCH programme. First, facilitation of the programme is variable and is dependent on local initiatives. Unless there are guidelines for the provision of GSFCH facilitation, this is likely to persist. Second, action learning is a useful form of facilitation and needs further research in health care. The recognition that facilitation requires funding when implementing end-of-life care frameworks/tools is perhaps relevant in light of the recent review of the LCP in the United Kingdom.²⁶ Nursing homes are known to have a weak context⁹ and therefore according to the Promoting Action on Research Implementation in Health Services framework¹⁰ require an HF model in order to implement and sustain new programmes. The evidence base concerning facilitation and implementation of the GSFCH²⁷ is limited. It would be interesting to report on the sustainability of the GSFCH programme in these 38 nursing homes in a few years' time.

The main limitation to this study is that it was not possible to randomise nursing homes receiving standard GSFCH facilitation. It may be that factors, other than the provision of facilitation, played a part in their implementation of the GSFCH programme.

Table 2. Generalised estimating equations: high facilitation trial arm and high facilitation and action learning trial arm.

Outcome	Intervention		Year			Interaction		Wald(2)	p
	High facilitation	High facilitation and action learning	Year 1	Year 2	Year 3	Action learning* (Year 2)	Action learning* (Year 3)		
Place of death (nursing home)	1	1.084 (0.607-1.933)	1	1.039 (0.712-1.515)	1.425 (0.926-2.191)	1.090 (0.672-1.767)	1.544 (0.893-2.672)	2.414	0.299
Advance care planning	1	0.999 (0.611-1.634)	1	1.311 (0.807-2.130)	2.480 (1.494-4.116)	1.016 (0.555-1.860)	1.211 (0.614-2.387)	0.333	0.847
Cardiopulmonary resuscitation decision in place	1	0.331 (0.145-0.754)	1	1.852 (1.003-3.418)	3.352 (1.613-6.967)	1.118 (0.510-2.453)	1.909 (0.668-5.453)	2.261	0.323
LCP/ICP/MP	1	0.221 (0.026-1.862)	1	2.026 (0.828-4.956)	6.945 (1.627-29.642)	1.289 (0.325-5.108)	7.705 (0.835-71.113)	6.670	0.036

LCP: Liverpool Care Pathway; ICP: Integrated Care Plan for the last days of life; MP: Minimum Protocol; Wald(2): Wald chi-squared with 2 degrees of freedom.

Table 3. Generalised estimating equations: observational group and the combined trial arms (high facilitation and high facilitation and action learning).

Outcome	Intervention		Year			Interaction		Wald(2)	p
	Observational group	Combined trial arms	Year 1	Year 2	Year 3	Combined trial arms* (Year 2)	Combined trial arms* (Year 3)		
Place of death (nursing home)	1	1.887 (1.004-3.544)	1	1.081 (0.848-1.378)	1.785 (1.320-2.413)	1.283 (0.868-1.896)	0.677 (0.403-1.138)	4.774	0.092
Advance care planning	1	1.076 (0.719-1.608)	1	1.319 (0.977-1.779)	2.747 (1.943-3.883)	1.534 (0.965-2.437)	1.210 (0.659-2.222)	3.306	0.191
Cardiopulmonary resuscitation decision in place	1	2.392 (1.176-4.863)	1	1.850 (1.255-2.725)	4.329 (2.515-7.453)	0.597 (0.360-0.989)	0.444 (0.212-0.932)	5.565	0.062
LCP/ICP/MP	1	5.102 (1.209-21.524)	1	2.069 (0.951-4.503)	15.199 (4.236-54.530)	0.605 (0.248-1.476)	0.191 (0.044-0.826)	5.747	0.057

LCP: Liverpool Care Pathway; ICP: Integrated Care Plan for the last days of life; MP: Minimum Protocol.

Conclusion

The amount of data collected within this study makes it one of the largest CRCT end-of-life care studies undertaken in care homes to date in the United Kingdom. The subsequent analysis of further data will help to inform a number of different aspects of end-of-life care for frail older people being cared for in care homes.

This study raises issues of providing funded facilitation that supports the nursing home organisation at both top-down and bottom-up levels in order to fully implement end-of-life care frameworks such as the GSFCH programme. Without such support, few care homes in this study fully implemented the GSFCH programme through to accreditation.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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References

- World Health Organization. *Good health adds life to years*, http://whqlibdoc.who.int/hq/2012/WHO_DCO_WHD_2012.2_eng.pdf (2012, accessed 4 January 2013).
- Age UK. *Improving later life. Understanding the oldest old*, <http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Improving%20Later%20Life%202%20WEB.pdf?dir=true%20> (2013, accessed 30 June 2013).
- Laing W. *Care of the elderly people: UK market survey 2011/12*. 24th ed. London: Laing & Buisson Publications Ltd, 2012.
- Department of Health. *End of life care strategy*. Fourth annual report, 2012, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf (2010, accessed 2 June 2014).
- Kinley J, Hockley J, Stone L, et al. The provision of care for residents dying in UK nursing care homes. *Age Ageing*. DOI: 10.1093/ageing/aft158, <http://ageing.oxfordjournals.org/content/early/2013/10/15/ageing.aft158.full.pdf+html?hwoaspc=true> (2013, accessed February 2014).
- Department of Health. *End of life care strategy*. London: Department of Health, 2008.
- Thomas K. *Caring for the dying at home*. Milton Keynes: Radcliffe Publishing Ltd, 2003.
- Gold Standards Framework Centre CIC. *The GSF Care Homes Training Programme: good practice guide*. Shrewsbury: National GSF Centre, 2011.
- Rycroft-Malone J, Harvey G, Scers K, et al. An exploration of the factors that influence the implementation of evidence into practice. *J Clin Nurs* 2004; 13: 913–924.
- Kitson A, Rycroft-Malone J, Harvey G, et al. Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. *Implement Sci* 2008; 3: 1.
- Hockley J. *Developing high quality end of life care in nursing homes: an action research study*. Unpublished Thesis, University of Edinburgh, Edinburgh, 2006.
- Clifford C, Badger F, Plumridge G, et al. Using the Gold Standards Framework in Care Homes: an evaluation of the phase 2 programme. Report available from: <http://www.gold-standardsframework.org.uk/contact-us>
- Hockley J, Watson J, Oxenham D, et al. The integrated implementation of two end of life care tools in nursing homes in UK: an in-depth evaluation. *Palliat Med* 2010; 24(8): 828–838.
- Watson J, Hockley J and Murray S. Evaluating effectiveness of the GSFCH and LCP in care homes. *End Life Care* 2010; 4(3): 42–49.
- Hockley J, Dewar B and Watson J. Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *J Res Nurs* 2005; 10(2): 135–152.
- McGill I and Brockbank A. *The action learning handbook*. Oxon: Routledge, 2004.
- Hockley J, Levy J, Heal R, et al. The use of action learning sets to enhance facilitation of the Gold Standards Framework in Care Homes end of life care home programme: the intervention arm of a cluster randomised control trial. In: *Poster presentation at the 19th International Congress on Palliative Care*, Montreal, QC, Canada, http://www.stchristophers.org.uk/sites/default/files/content/38658CH_St_Chris_Jo_Hockley_Poster.pdf (2012, accessed August 2013).
- Wells T and Linton S. Out of hours care. *Health Serv J*, <http://www.hsj.co.uk/rcsource-centre/your-ideas-and-suggestions/out-of-hours-care/5013998.article> (2010, accessed 14 January 2014).
- Handley M, Goodman C, Froggatt K, et al. Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision – a prospective study. *Health Soc Care Community* 2014; 22(1): 22–29.
- Sims-Gould J, Wiersma E, Arseneau L, et al. Care provider perspectives on end-of-life care in long-term-care homes: implications for whole-person and palliative care. *J Palliat Care* 2010; 26(2): 122–129.
- Stone L, Kinley J and Hockley J. Advance care planning in care homes: the experience of staff, residents and family members. *Int J Palliat Nurs* 2013; 19(11): 550–557.
- Hewison A, Badger F and Swani T. Leading end-of-life care: an action learning set approach in nursing homes. *Int J Palliat Nurs* 2011; 17(3): 135–141.
- Thomas K. *The GSF in Care Homes Training programme* (personal communication). Shrewsbury: GSF Centre, 2012.
- Forder J and Allan S. *Competition in the English nursing homes market*. Personal Social Services Research Unit,

- University of Kent, <http://www.pssru.ac.uk/archive/pdf/dp2820.pdf> (2011, accessed August 2013).
25. Hockley J, Kinley J and Stewart R. The use of action learning sets to enhance facilitation of the Gold Standards Framework in Care Homes end of life programme: the intervention arm of a cluster randomised control trial (Abstract accepted for EAPC). *J Palliat Care* 2012; 23(3): 228.
 26. Neuberger J, Aaronovitch D, Bonser T, et al. *More care, less pathway: a review of the Liverpool Care Pathway*. Department of Health, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (2013, accessed 28 July 2013).
 27. Kinley J, Froggatt K and Bennett M. The effect of policy on end-of-life care practice within nursing care homes: a systematic review. *Palliat Med* 2013; 27(3): 209–220.

Appendix Two: Palliative Medicine paper reporting the outcome systematic review

Palliative Medicine

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The effect of policy on end-of-life care practice within nursing care homes: A systematic review

Julie Kinley, Katherine Froggatt and Michael I Bennett

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The online version of this article can be found at:

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What is This?

The effect of policy on end-of-life care practice within nursing care homes: A systematic review

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Abstract

Background: The number of older people in the UK is increasing. A significant proportion of end of life care for this population is currently provided and will increasingly be provided within nursing care homes.

Aim: To identify the impact of implementing end of life care policy with regard to the use of the Gold Standards Framework in Care Homes programme, the Liverpool Care Pathway (or an Integrated Care Pathway) and educational/training interventions to support the provision of end of life care within nursing care homes within the UK.

Design: Systematic literature review of published literature and reports.

Data sources: An electronic search was undertaken of five databases-Medline, CINAHL, EMBASE, Web of Science and the Cochrane library and websites of government and palliative care organisations for papers and reports published between 2000 to June 2010. The reference lists of studies that were retrieved for the detailed evaluation were hand-searched for any additional relevant citations.. Only studies that included comparative outcome data were eligible for inclusion.

Results: Eight papers/reports, incorporating information from three studies were identified. Two studies reported on the implementation of the Gold Standards Framework in Care Homes programme and one the implementation of an Integrated Care Pathway for the last days of life. Improvements occurred in resident outcomes and in relation to staff recognising, managing and meeting residents needs for end of life care.

Conclusions: The studies provided limited evidence on improved outcomes following the implementation of these interventions. Further research is needed, both within the UK and internationally, that measures the process and impact of implementing these initiatives.

Keywords:

Review, systematic review, outcomes, policy, nursing homes, long term care, homes for the aged, education, terminally ill, terminal care

Introduction

The world's population is increasing both in age and number. The provision of healthcare for this growing population has consequently become an important worldwide consideration.¹ Within the UK, planning to provide care for the increasing numbers of older people is already raising a number of issues for individuals, families, healthcare professionals and also organizations. Care homes represent one such organization. These establishments provide accommodation, together with nursing or personal care.²

The elderly UK population has increased and is predicted to continue to increase so that 22% of the population in England and Wales will be aged 65 and over by 2030.³ A

similar trend has been identified in Scotland.⁴ In addition to these demographic changes, hospices and hospitals are discharging patients with acute care needs and patients with end-of-life care needs into nursing care homes (NCHs). These changes mean there are, and will continue to be, increasing numbers of older people who are frail and have complex health needs both living and dying in NCHs.⁵

There seems to be recognition within the UK of these changes as a number of recent policies to promote quality end-of-life care into all settings have included NCHs.^{4,6} These policies propose that education, training and mentoring in the principles of end-of-life care will enable the NCHs to address this.^{4,6-8} Within an NCH context the Gold

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Standards Framework in Care Homes (GSFCH) programme, which incorporates advance care planning (ACP), is recognized as a possible mechanism to achieve this.^{4,6,8} Implementation of the Liverpool Care Pathway (LCP) or its equivalent is also recommended.^{4,6} These recommendations are set against a care home context, which in a study undertaken within eight NCHs, was identified as having: a lack of palliative care knowledge and skills; a pervading culture of 'striving to keep alive'; not taking responsibility for recognizing dying; a lack of multidisciplinary collaboration; fear of talking about dying; and resistance to change.⁹ Whilst these are significant issues they may not be universal to all NCHs. However where such issues are present they need to be addressed in order for the NCH residents to receive the quality end-of-life care that the government is promoting.

The *Gold Standards Framework in Care Homes* is a system-based organizational approach, developed in 2004, to optimize the end-of-life care provided by generalists within a care home context. The aim of the programme is to enable care homes to gradually incorporate the GSFCH framework until it becomes standard practice. To enable care homes to achieve this, the focus is on addressing seven key issues in end-of-life care termed the 7Cs.¹⁰ *Integrated Care Pathways* (ICPs) are multidisciplinary documents that detail essential steps in caring for specific groups of patients with a specific clinical problem.¹¹ The *Liverpool Care Pathway* was developed in 2001 and is an example of an ICP. It is a multiprofessional document that provides an evidence-based framework to guide, prompt and inform the care of patients and their families in the last days of life.¹² Since its conception the LCP has been adapted for other care settings including NCHs.¹³

The LCP and GSFCH were originally designed for, and then used within, primary care practice. These interventions were subsequently adapted for use within other settings which included NCHs. NCH residents, unlike the residents of care homes providing personal care, have a higher dependency and consequently access to 24-hour on site nursing care. Evidence is lacking, however, on how effective these approaches are to the provision of end-of-life care in NCHs. A literature review was undertaken in 2006¹⁴ looking at end-of-life care in long-term care settings for older people. Whilst this review identified 25 papers that addressed modes of service delivery, they mainly reported small-scale descriptive accounts of interventions and developments. A recent Cochrane review¹⁵ was undertaken to determine the effectiveness of multi-component palliative care service delivery for older people living in NCHs. Only three studies were identified, all of which were undertaken in the USA. As no systematic literature review has been undertaken to report on the impact of the UK policy recommendations on the provision of end-of-life care within an NCH setting, we sought to define the evidence base as it currently stands.

Methods

Aim

This review aims to identify the impact of implementing end-of-life care policy with regard to the use of the GSFCH, the LCP (or an Integrated Care Pathway^a (ICP) for the last days of life) and educational/training interventions to support the provision of end-of-life care within a UK NCH context.

Search strategy

As the GSF was developed in 2000 and the LCP in 2001, Medline, CINAHL, EMBASE, Web of Science and the Cochrane library were searched by JK for papers and reports published between 2000 and June 2010. Websites of government and palliative care organizations were also searched. The search strategy for Medline is shown in Appendix 1.

The reference lists of studies that were retrieved for the detailed evaluation were hand-searched for any additional relevant citations. Once retrieved each additional article was reviewed before accepting it into the review or rejecting it. Whilst specific journals and the grey literature were not hand-searched, the final list of retrieved articles was sent to four experts alongside the inclusion and exclusion criteria to ensure there had been no omissions.

Studies included in the review were randomized controlled trials, meta-analyses, systematic reviews, cohort studies, case control studies or case series – as long as they included comparative data.

Inclusion criteria

Only adult UK NCH residents, their relatives and the staff working within these NCHs were included. This decision was made because as the resident population in NCHs and care homes providing personal care vary substantially so does their need for care and thus care provision. In addition, within the care home context, implementation of these tools has mainly been within NCHs. Participants from dual-registered homes (providing nursing and personal care) were included as long as details pertaining to the NCH residents could be extrapolated or where the majority of the sample was NCH residents. Finally only studies written in the English Language, published between 2000 and 2010 and reporting on the implementation of the GSF, LCP (or ICP) or a palliative care/end-of-life care educational and/or training initiative were included.

In the data extraction stage, if duplicate studies – that is, those including the same study population but reported in different journals – were found, the data would be synthesized so the study would be included only once.

Exclusion criteria

Studies were excluded if they primarily involved implementing any intervention to develop end-of-life care

provision other than the GSFCH programme, the LCP or ICP or an educational and/or training initiative. They were also excluded if they were undertaken in NCH homes outside the UK or were undertaken in care homes providing personal care or where the majority of the residents in the study were from these care homes.

Data extraction

Data extraction was undertaken by JK, with a sample reviewed by KF. For each study that met the inclusion criteria the following information was identified: study design, the level of evidence and the study sample. Where present, data were extracted on the effect of each of the identified interventions on:

- i. outcomes related to the resident
- ii. outcomes related to the staff but reported as resident/family outcomes
- iii. outcomes relating to family
- iv. outcomes relating to staff

For residents and their families, outcomes identified by the GSFCH¹⁶ are reported on: communication; coordination; control of symptoms; continuity; carer bereavement support; care of the dying; increased collaboration with other primary care and palliative care specialists; a reduction in both crisis admissions to hospital and in the proportion of NCH residents dying in the hospital. We recorded data on the following outcomes for staff: knowledge; skills and/or behaviour. The outcomes for staff incorporate those that were reported as a resident/family outcome but where this reported outcome could only have occurred *following* a change in staff knowledge, skills and/or behaviour. All reported outcomes are included – both measurable (explicit outcomes) and outcomes that were implied/understood to have occurred (implicit outcomes). Outcomes for all participants could be reported by either themselves, residents and their family/friends or other professionals.

Results

The search (see Figure 1) identified eight articles, reporting on three primary studies that fully met the inclusion criteria.^{17–24} The three studies were all graded as non-analytical case series studies²⁵ and they report the effect of implementing these interventions within a total of $n = 64$ NCHs. The review summarizes data from: the Phase 2 National GSFCH programme^{17–20}; the Phase 4 National GSFCH programme^{21,22}; and the implementation of an ICP.^{23,24} Further details of the study design and study sample are provided in Table 1.

Outcomes are reported from the GSFCH programme, the LCP/ICP and finally from education/training inter-

ventions with respect to their impact on the resident/their family and staff. Both explicit (clearly stated and evidenced) outcomes and implicit (implied) outcomes are reported.

Where applicable the PRISMA publication guidelines for systematic reviews have been adhered to.

GSFCH

Two studies were identified that measure, through comparative data, the outcome of implementing the GSFCH programme in UK NCHs.^{17,22} Only one study reported statistical analysis of their comparable outcome data¹⁷ – those outcomes they identified as statistically significant are included in this review. All measurable (explicit) and reported (implicit) outcomes are included.

Measurable resident outcomes of the GSFCH

The GSFCH intervention had a direct and measurable effect on five resident outcomes: communication; continuity care of dying; reduction in the proportion of NCH residents dying in the hospital; and reduction in crisis admissions to hospital and crisis events (Table 2).

In relation to communication, there was an increase in the documentation of plans for 'do not attempt resuscitation' (DNAR) and ACP in the NCHs following the interventions implementation (Table 2).¹⁷ Change in the continuity of care for residents was identified by an increase in the availability of 'when necessary' or 'prn' medication (Table 2).¹⁷ This demonstrated that provision had been made for the ongoing care of the resident even when their condition/needs changed. Whilst the majority of dying residents were not cared for using a 'last days of life' pathway, the intervention increased the use of this pathway (Table 2).^{17,22} The increased use of 'a last days of life' pathway is supportive of the GSFCH programme impacting on both recognition of and care of the dying.²²

Following the implementation of the GSFCH there was a reduction in the number of hospital admissions from 31% at baseline to 24% following the intervention. Consequently, the number of inappropriate days spent in hospital in the last two months of life also reduced from 82% at baseline to 44% following the implementation of the GSFCH (i.e. a reduction of 38%) (Table 2).²² Not surprisingly then, and occurring at the same time, was the effect of the intervention on place of death. This finding was supported by both studies. The proportion of inappropriate (criteria stated) hospital deaths reduced from 15% at baseline to 8% post-programme implementation, or a reduction of 7%²² and the percentage of residents who died in the care home increased from 80.9% at baseline to 88.5% following the intervention (an increase of 8%).¹⁷ It was additionally reported that over a six-month period the number of residents who had no cri-

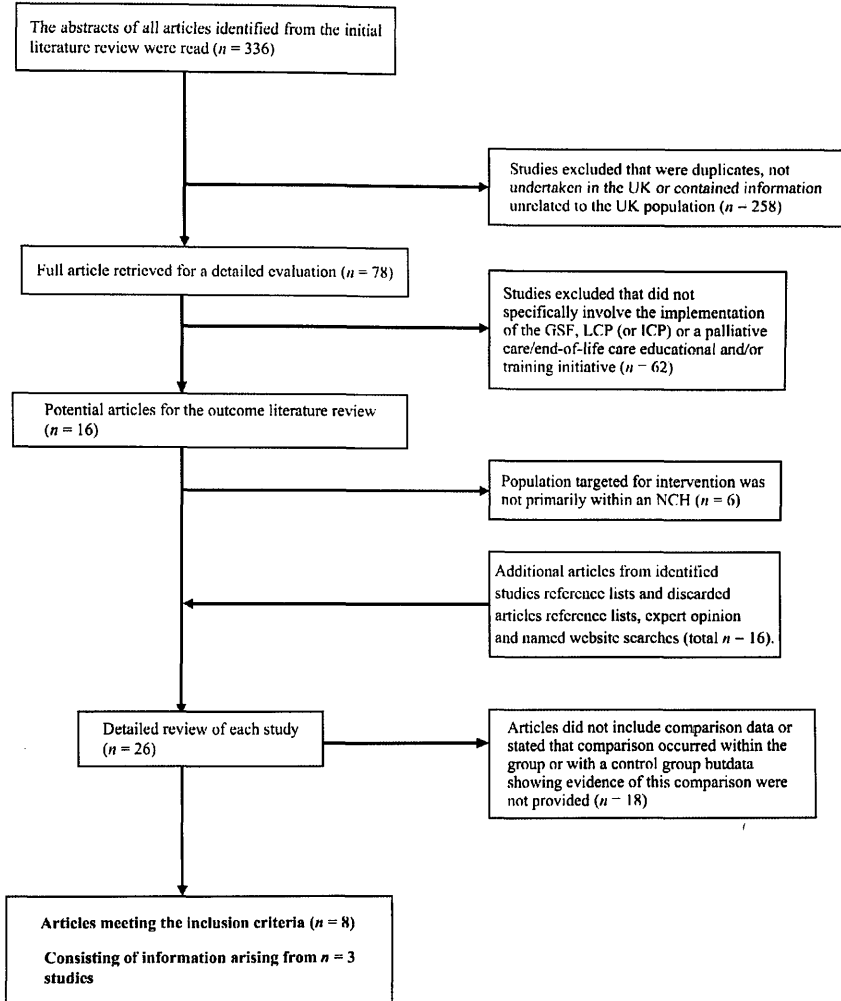


Figure 1. Flow chart of the review process.

sis events increased from 51.9% to 61.2% and the number of residents who had no crisis admissions increased from 62.1% to 73.7%.¹⁷

Reported staff outcomes which potentially impacted on resident/family outcomes

A number of additional implicit resident and family outcomes were reported by staff completing an audit questionnaire

prior to and following the GSFCH implementation.¹⁷ These outcomes could only have occurred as a consequence of the GSFCH programme impacting on staff behaviour first (Table 3). In relation to residents: the occurrence of discussing plans for cardiopulmonary resuscitation with them increased from 23% 'pre' intervention to 65% 'post' intervention; the use of a register enabling the identification of end-of-life care needs increased from 21% 'pre' intervention to 88% 'post' intervention; and the

Table 1. Quality of the included studies and their participant numbers.

Study	Design	Level of evidence ²⁵	Recommendation for practice ^{26,25}	Number of NCHs and their participants
Clifford et al. (2007)	Non-analytical case series	Level 3	Grade D	Original sample 79 NCHs and, of these, 2 were not NCHs. NCHs providing 'pre' and 'post' data $n = 49$ Three samples: 1. Key coordinators from $n = 49$ NCHs 2. Residents who died during their stay in the NCH from $n = 44$ NCHs 'pre' intervention $n = 220$ residents 'post' intervention $n = 219$ residents 3. Residents who actually died within the NCH from $n = 44$ NCHs 'pre' intervention $n = 178$ residents 'post' intervention $n = 192$ residents
Hockley et al. (2008)				$n = 7$ NCHs Three samples: 1. Residents who died during their stay in the NCH 'pre' intervention $n = 95$ residents 'post' intervention $n = 133$ residents 2. Key coordinators $n =$ not given 3. Bereaved relatives from $n = 5/7$ NCHs 'pre' intervention $n = 22$, 'post' intervention $n = 14$
Hockley et al. (2004)				$n = 8$ NCHs Residents who actually died in the NCH 'pre' intervention $n = 30$ residents 'post' intervention $n = 41$ residents

*hierarchy of evidence ranging from Grade 1 which includes RCT to Grade 4 which refers to evidence arising from expert opinion.

**Ranges from A-D where D represents the lowest grade in terms of recommendation for practice.

number of NCHs who described themselves as routinely undertaking ACP increased from 51% 'pre' intervention to 77% 'post' intervention.¹⁷

In relation to care of the dying, implementing the GSFCH intervention resulted in an increase in the: use of a protocol in the last days of life from 51% 'pre' intervention to 78% 'post' intervention; use of an ICP from 19% 'pre' intervention to 59% 'post' intervention; and use of a procedure for anticipatory prescribing from 39% 'pre' intervention to 70% 'post' intervention (Table 3). The care home staff completing the audit questionnaire stated that there had been an increase in the quality of care offered to residents in relation to end-of-life care as being 'very good', increasing from 29% 'pre' intervention to 57% 'post' intervention.

Regarding family outcomes, care home staff completing the audit questionnaire reported an increase from 20% 'pre' intervention to 42% 'post' intervention in their ability to provide 'very good' support to family carers in relation to end-of-life care. The occurrence of discussing plans for cardiopulmonary resuscitation with the family was reported to have increased from 38% 'pre' intervention to 81% 'post' intervention (Table 3). Finally, the provision of written information to the family was documented on the after death analyses (ADAs) completed by 44 NCHs to have increased from 20.2% 'pre' intervention to 52.9% 'post' intervention.

Overall outcome of the GSFCH according to bereaved relatives

Data arising from interviewing relatives ($n = 22$) 'pre' intervention and ($n = 14$) 'post' intervention from five NCHs were analyzed within and across all NCHs through the use of a matrix.²² Data arising from all interviews in the participating NCHs relating to an aspect of the 7Cs of the GSFCH programme were tabulated in the matrix. The matrix was then used to measure and document change in the balance of outcomes of the GSFCH 7Cs as a result of the intervention. The use of a matrix to quantify a qualitative process was an unusual method to use to interpret the data. However, whilst the matrix is not a validated tool, improvement was reported to have occurred: there was an overall increase in positive outcomes and a decrease in negative outcomes as a consequence of the GSFCH programme when considered across five NCHs.

Reported staff outcomes

Staff outcomes were reported from two sources. Key coordinators ($n =$ not given) working within the NCHs and implementing the GSFCH programme stated that their knowledge, skill and confidence in different aspects of palliative care increased from 50% 'pre' intervention to 85%

Table 2. Measurable (explicit) outcomes relating solely to residents.

Resident outcome	Population	Evidence	'Pre' intervention	'Post' intervention	Who identified the change	Reference		
Communication	n = 178 residents 'pre' intervention and n = 192 residents 'post' intervention (from 44 NCHs) n = 6 NCHs	Recorded on the ADA _s ^(a) the resident had an ACP ^(b) in place	67 (37.6%)	121 (63%)*	Staff within the NCH	Clifford et al. (2007)		
		Documented DNAR ^(c) within deceased resident's records	6.3% 35% 0% 0% 8% 4%	80% 59% 69% 50% 73% 79%	Researcher/facilitator	Hockley et al. (2008)		
		Documented ACP ^(b) /within deceased resident's records	6.3% 0% 0% 0% 15% 4%	50% 36% 62% 50% 60% 79%				
		Recorded on the ADA _s ^(a) the resident had PRN ^(d) drugs listed	94 (53.7%)	116 (60.4%)*	Staff within the NCH	Clifford et al. (2007)		
		Continuity	n = 178 residents 'pre' intervention and n = 192 residents 'post' intervention (from 44 NCHs)	Non-essential medication discontinued	46%	66%		
				resident's case notes and 'post' from ICP documentation				
				Use of antibiotics in the last days of life	33%	5%		
				resident's case notes and 'post' from ICP documentation				
				Recorded on the ADA _s ^(a) the resident had a last days of life 28 pathway	28 (15.9%)	87 (45.8%)*	Staff within the NCH	Clifford et al. (2007)
		Care of dying	n = 178 residents 'pre' intervention and n = 192 residents 'post' intervention (from 44 NCHs) n = 5 NCHs	Documented NCHA use of the LCP for the last days of life within deceased resident's records	0% 0% 0% 0% 12.5%	72% 57% 13% 12.5% 63%	Researcher/facilitator	Hockley et al. (2008)
Documented NCHA	0%			72%				
use of the NCH B	0%			57%				
LCP for the NCH C	0%			13%				
last days of life within NCH D	0%			12.5%				

(Continued)

Table 2. (Continued)

Resident outcome	Population	Evidence	'Pre' intervention	'Post' intervention	Who identified the change	Reference
Reduction in the proportion of NCH residents dying in the hospital	n = 220 residents 'pre' intervention and n = 217 residents 'post' intervention (from 44 NCHs)	Recorded on the ADA ^(a) the resident's place of death was the care home	178 (80.9%)	192 (88.5%)*	Staff within the NCH	Clifford et al. (2007)
Reduction in crisis admissions to hospital and crisis events	n = 95 residents 'pre' intervention and n = 133 residents 'post' intervention (from 7 NCHs) n = 220 residents 'pre' intervention and n = 219 residents 'post' intervention (from 44 NCHs)	Documented number of inappropriate hospital deaths within deceased resident's records Recorded on the ADA ^(a) the resident had no crisis admissions to hospital in their last 6 months of life	14/95 (15%) 110 (62.1%)	11/133 (8%) 151 (73.7%) *	Researcher/facilitator Staff within the NCH	Hockley et al. (2008) Clifford et al. (2007)
	n = 95 residents 'pre' intervention and n = 133 residents 'post' intervention (from 7 NCHs)	Recorded on the ADA ^(a) the resident had no crisis events (defined as urgent request for help) in their last 6 months of life	94 (51.9%)	126 (61.2%)*		
	n = 95 residents 'pre' intervention and n = 133 residents 'post' intervention (from 7 NCHs)	Documented number of hospital admissions in the last 8 weeks of life within deceased resident's records	29 (31%)	32 (24%)	Researcher/facilitator	Hockley et al. (2008)
		Documented inappropriate days (defined as a resident over 88 years old with dementia, who was deteriorating from their dementia over several weeks and who then subsequently died within 2-3 days of pneumonia) spent in hospital in the last 2 months of life within deceased resident's records	141/171 inappropriate bed days (82%)	84/190 inappropriate bed days (44%) **		

*statistically significant

**There were two 'equivocal' admissions to hospital and if these were included there was still a reduction of 21% in inappropriate hospital bed days post-GSFCH.

(^a) ADA = After Death Analysis

(^b) ACP = Advance Care Plan

(^c) DNAR = Do Not Attempt Cardiopulmonary Resuscitation

(^d) PRN = When necessary

1

Table 3. Reported (implicit) staff outcomes that also had an effect on resident/family outcomes (* = statistically significant).

Staff outcome	Resident/family outcome	Population	Evidence	'Pre' intervention	'Post' intervention	Who identified the change	Reference
Behaviour	Communication	n = 49 NCHs	Stated they had a register for end-of-life needs	21%	88%*	A key coordinator of the GSFCH programme	Clifford et al. (2007)
			Stated that the NCH discussed plans for cardiopulmonary resuscitation with the resident	23%	65%*		
			Stated they routinely undertake ACP ^(b)	51%	77%*		
			Stated that the NCH discussed plans for cardiopulmonary resuscitation with GP	42%	71%*		
	Continuity		Stated that the NCH send a handover form to out-of-hours GP	17%	52%*		
	Coordination		Stated they had a coordinator for end-of-life care	41%	83%*		
	Control of symptoms		Stated that the home's ability to address a resident's physical needs was 'very good'	49%	75%*		
			Stated that the home's ability to address a resident's spiritual needs was 'very good'	17%	24%*		
	Care of dying		Stated that in relation to end-of-life care the quality of care offered to residents was 'very good'	29%	57%*		
			Stated that the NCH use a care protocol in the last days of life	51%	78%*		
			Stated that the NCH use an ICP	19%	59%*		
			Stated that the NCH have a procedure for use of anticipatory medication	39%	70%*		
	Carer bereavement support		Stated that in relation to end-of-life care, quality of support to family carers was 'very good'	20%	42%*		
			Stated that the NCH discussed plans for cardiopulmonary resuscitation with the family	38%	81%*		
		n = 178 residents 'pre' intervention and n = 192 residents 'post' intervention (from 44 NCHs)	Stated on the ADAs ^(a) an increased use of written information provided to the family	35 (20.2%)	101 (52.9%)*	Staff within the NCH	

(^a) ADA = After Death Analysis; (^b) ACP = Advance Care Plan

'post' intervention following the 'Foundations in Palliative Care' course.²² Similarly, in relation to end-of-life care a key coordinator of the GSFCH programme stated that use of 'Foundations in Palliative Care' as a resource within the care home increased from 18% 'pre' intervention to 52% 'post' intervention of the care homes in the study (though the impact and effect of this is not given) and that support to staff had increased from 12% 'pre' intervention to 24% 'post' intervention.¹⁷

ICP

Only one study reported the effect of just implementing an ICP 'adapted LCP'.²³

Measurable resident outcomes of the ICP

One study reported discontinuation of non-essential medication in the last days of life (from 46% of residents at baseline to 66% of residents following the intervention) whilst at the same time the use of 'prn' medication increased from 23% to 93%.²³ A reduction in the use of antibiotics in the last days of life (from 33% of residents at baseline to 5% of residents following the intervention) was also recorded.²³

The measurable resident and staff outcomes of the ICP

The ICP intervention had a direct and measurable joint effect on staff skill and residents' symptom control. NCH staff completing the ICP documentation reported an increase in the recording and treatment of three end-of-life care symptoms. The treatment of these symptoms increased with respect to: agitation from 33 'pre' intervention to 100% 'post' intervention; pain from 75% 'pre' intervention to 100% 'post' intervention; and respiratory secretions from 18% 'pre' intervention to 100% 'post' intervention.

Educational/training interventions to support the provision of end-of-life care

No study was identified that provided comparative data measuring the effect of implementing a palliative care education/training intervention to support the provision of palliative care within a UK NCH.

Discussion

Although this review relates to policy within the UK, these findings are relevant in other countries and healthcare systems that seek to introduce such end-of-life tools and education and training. The promotion of these initiatives within the UK has resulted in 1500 care homes undertaking the GSFCH programme.²⁶ International interest in this initiative is recognized with the availability of a policy to enable this to occur.²⁶ The LCP/ICP has had similar appeal

with at least 18 countries outside the UK reported as utilizing it within care homes, hospitals and the community.²⁷ It is clearly adaptable for international use. The findings from this review demonstrate that whilst the LCP/ICP and GSFCH are promoted as interventions to support the provision of end-of-life care in the NCH context, the evidence currently available is limited.¹⁷⁻²⁴ Only three studies actually met the inclusion criteria. No study meeting the inclusion criteria had a control group. The findings therefore need to be interpreted with caution as it is not possible to be certain that the outcomes reported within this review occurred solely as a consequence of the intervention. A number of broader factors may have shaped the outcomes of the interventions related to: the presence of pre-existing factors; the process by which the intervention was implemented; and the evaluation data collection methods used. In addition, no study used validated data collection tools or described evidence of sustained change.

No study reporting on the implementation of an end-of-life care educational/training intervention actually met the inclusion criteria. In relation to end-of-life care within NCHs within the UK there is currently a lack of outcome evidence regarding the value of education and training on actual practice and therefore its use as a singular initiative is questionable. Interestingly, the GSFCH intervention included a blend of all three interventions as education/training initiatives and implementing the LCP/minimum protocol for the last days of life are encouraged as part of its implementation. This blended approach may result in the best outcomes regarding the provision of end-of-life care.

This review has highlighted the challenge of identifying and measuring outcomes from policy recommendations where explicit outcomes have not been established. The GSFCH programme and the LCP outcomes were used within this review to capture the impact of transferring end-of-life care policy from theory to practice in UK NCHs. It is, however, questionable as to whether the end-of-life care provision in NCHs can just be evidenced through the implementation of these two end-of-life care systems rather than the NCH meeting specific and explicit end-of-life care outcomes evidenced in practice. What needs to be urgently decided is who defines, measures and reports outcomes concerning the provision of end-of-life care in NCHs. Answers to these questions are challenging as achieving quality end-of-life care in NCHs is complex and important to multiple individuals – residents, families, healthcare professionals, organizations and also to society as a whole.

Within England, the Care Quality Commission (CQC) acts as an independent regulator of healthcare and adult social care services. Care is regulated against 38 standards with one standard relating to dying and death.²⁸ Whilst this guidance exists, specific details for the staff on how to achieve each element of it in practice, and how outcomes will be measured by CQC, are not provided. Non-statutory guidance⁸ does exist in England to guide the provision and

the evaluation of end-of-life care actually provided by a service. Its value may be limited, however, as it is neither financed nor mandatory. It may well be that for end-of-life care to be integrated into care and universally provided within all NCHs, mandatory regulation of this should occur via such regulatory boards. The focus could be on care, rather than systems and process, giving users a bigger voice about the treatment, care and support they have received.²⁹ In addition to regulation of care, commissioning of care (particularly continuing care) is a growing consideration for NCHs within the UK. It may be that in future the specifications of commissioners become increasingly important.

This review alongside the recent Cochrane review¹⁵ highlight the fact that further research on the provision of end-of-life care to residents within UK NCHs and the process involved when transferring and sustaining end-of-life care policy into practice needs to be undertaken. It is important for this to identify explicit outcomes and then determine what NCHs actually need to have in place for them to achieve and then sustain these outcomes in practice. Whilst these end-of-life care tools are UK-based developments, their use internationally would present an additional opportunity to develop such knowledge – a process that has already started with the implementation of the LCP.³⁰

Whatever the system and wherever the system is implemented, bringing about change raises similar issues of process and a similar need to demonstrate outcomes. Until such outcomes are defined future studies should utilize the explicit outcomes identified by this review which include: the resident's documented place of death; the number of crisis admissions to hospital in their last six months of life; and the presence of a documented ACP and DNAR form. This research should include 'pre' and 'post' comparative data.

Limitations of the review

This review only utilized data available from UK NCH studies. Whilst there is variety in the systems and residents within UK NCHs it was the intention of this review to report outcomes that arose from, and so were directly applicable to, the end-of-life care of residents, their families and the staff caring for them in the NCH setting as a consequence of UK policy.

When undertaking the systematic review a number of studies were identified that had outcome data but provided no comparative data. They were therefore excluded from this review. Their 'post' intervention findings, however, may have provided additional evidence of the perceived, but not measured, effect of these interventions.

Conclusion

The numbers of the UK population living and therefore dying in NCHs is increasing and this trend is predicted to continue. This means there is a need to ensure quality

end-of-life care is provided by those working, and for those living, within these homes. Whilst the outcomes identified from this systematic review are from a limited evidence base (three studies) they do provide evidence of change in staff, resident and family outcomes following the implementation of both the GSFCH and ICP interventions. Improvements occurred in resident outcomes and in relation to staff recognizing, managing and meeting residents' needs for end-of-life care. Ongoing research is now needed both within the UK and internationally to measure the impact of these initiatives on end-of-life care outcomes within NCHs.

Appendix I

Electronic search history for Medline which was amended as necessary for other databases

1. nursing home*
2. exp nursing home
3. 1 or 2
4. long-term care
5. exp long-term care
6. 4 or 5
7. palliative care
8. exp palliative care
9. terminally ill
10. exp terminally ill
11. hospice*
12. end adj of adj life
13. 7 or 8 or 9 or 10 or 11 or 12
14. 3 or 6
15. 13 and 14
16. limit 15 to aged 65+ years and aged 80 and over
17. limit 16 to English
18. gsf.mp
19. gold adj standards adj framework
20. gsfch.mp
21. gold adj standards adj framework adj in adj care adj homes
22. liverpool care pathway.mp
23. LCP.Mp
24. integrated care pathway.mp
25. ICP.mp
26. education.mp
27. training.mp
28. 26 or 27
29. 17 and 28
30. 18 or 19 or 20 or 21
31. 17 and 30
32. 22 or 23 or 24 or 25
33. 17 and 32
34. 29 and 31 and 33 – limited to publications 2000–2010 and minus duplicates

Note

- ^a within this literature review all subsequent references to an ICP relate specifically to the use of an ICP for the last days of life.

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Conflict of Interest

The authors declare that there is no conflict of interest.

References

- Hall S, Petkova H, Tsouros A, Constantini M and Higginson I. *Palliative care for older people: better practices*. Denmark: World Health Organisation, 2011.
- Department of Health 'Care Standards Act (2000)', www.legislation.gov.uk/ukpga/2000/14/section/3 (2000).
- Gomes B and Higginson I. Where people die (1974–2030): past trends, future projections and implications for care. *Palliative Medicine* 2008; 22: 33–41.
- The Scottish Government. 'Living and dying well. A national plan for palliative and end of life care in Scotland', www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf (2008).
- Care Quality Commission. 'Headline Statistic Spreadsheet', www.cqc.org.uk/guidanceforprofessionals/socialcare/care-providers/statisticsonregisteredproviders.cfm (2010).
- Department of Health. *End of life care strategy*. London: Department of Health, 2008.
- The Scottish Commission for the Regulation of Care 'Better care every step of the way', www.carecommission.com/index.php?option=com_content&task=view&id=6828&Itemid=168 (2009).
- Department of Health. *End of life care strategy quality markers and measures for end of life care*. London: Department of Health, 2009.
- Watson J, Hockley J and Dewar B. Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing* 2006; 12(5): 234–240.
- Thomas K, Sawkins N and Stobbart-Rowlands M. *The GSF Care Homes Training Programme Good Practice Guide Phases 6/7*. Walsall, UK: National GSF Centre, 2009.
- Campbell H, Hotchkiss R, Bradshaw N and Porteous M. Integrated care pathways. *British Medical Journal* 1998; 316: 133–137.
- Jack B, Gambles M, Murphy D and Ellershaw J. Nurses' perception of the Liverpool Care Pathway for the dying patient in the acute hospital setting. *International Journal of Palliative Nursing* 2003; 9(5): 234–240.
- Ellershaw J and Murphy D. The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying. *International Journal of Palliative Nursing* 2005; 11(3): 132–134.
- Froggatt K, Wilson D, Justice C, MacAdam M, Leibovici K., Kinch J et al. End-of-life care in long-term care settings for older people: a literature review. *International Journal of Older People Nursing* 2006; 1: 45–50.
- Hall S, Koliakou A, Petkova H, Froggatt K and Higginson I. Interventions for improving palliative care for older people living in nursing care homes. *Cochrane Database of Systematic reviews* 2011. Issue 3. Art. No.: CD007132. DOI: 10.1002/14651858.CD007132.pub2
- National GSFCH Centre. 'The Gold Standards Framework in Care Homes briefing paper', www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/FINAL%20GSF%20BRO%20CHBP.pdf (2009).
- Clifford C, Badger F, Plumridge G, Hewison A and Thomas K. 'Using the Gold Standards framework in care homes: An evaluation of the Phase 2 programme', www.healthsciences.bham.ac.uk/research/life/GSFCH_report_June_2008.pdf (2007).
- Badger F, Thomas K and Clifford C. Raising standards for elderly people dying in care homes. *European Journal of Palliative Care* 2007; 14(6): 238–241.
- Badger F, Clifford C, Hewison A and Thomas K. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. *Palliative Medicine* 2009; 23: 502–511.
- Thomas K, Sawkins N, Clifford C and Badger F. 'Journey's End', www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/GSFCH_Poster.pdf (2006).
- National GSFCH Centre. 'Summary of evidence for Gold Standards Framework Care Homes Training Programme', www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/Summary%20of%20GSFCH%20Evidence%20of%20Effectiveness%20Feb%2010%20v3%20FINAL.pdf (2010).
- Hockley J, Watson J and Murray S. 'The Midlothian "Gold Standards Framework in Care Homes" project'. www.healthcareforlondon.nhs.uk/assets/End-of-life-care/Midlothian-GSFCH-project.pdf (2008).
- Hockley J, Dewar B and Watson J. *St Columba's Hospice BRIDGES initiative project. Phase 111. Developing quality end of life care in eight independent nursing homes through the implementation of an integrated care pathway*

- for the last days of life. Edinburgh: St Columba's Hospice, 2004.
24. Hockley J, Dewar B and Watson J. Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *Journal of Research in Nursing* 2005; 10(2): 135–152.
 25. Scottish Intercollegiate Guideline Network (SIGN). *SIGN 50: A guideline developers' handbook. Section 6: Forming guideline recommendations*. Edinburgh: Scottish Intercollegiate Guideline Network. www.sign.ac.uk/guidelines/full-text/50/sections6.html (2008).
 26. Gold Standards Framework Central Team, www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/CI1%20one%20page%20insert.pdf
 27. The Marie Curie palliative Care Institute Liverpool, www.mcpcil.org.uk/liverpool-care-pathway/national-international/index.htm
 28. Department of Health. *Care Homes for Older People. National Minimum Standards*. London: Department of Health, 2000.
 29. Care Quality Commission. 'The essential standards of quality and safety you can expect', www.cqc.org.uk/usingcare-services/essentialstandardsqualityandsafety.cfm (2011b, accessed February 2011).
 30. Veerbeek L, van der Heide A, de Vogel-Voogt E, de Bakker R, van der Rijt C, Swart S et al. Using the LCP: bereaved relatives' assessments of communication and bereavement. *American Journal of Hospice and Palliative Medicine* 2008; 25(3): 207–214.

Appendix Three: PRISMA checklist for the process systematic literature review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	79
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria; participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	---
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	79
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	79
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	80
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	80
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	80 (only search terms)
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	80-82 and 84
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	82-83
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	---
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	---
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	---
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	82-83

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	---
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	---
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	83
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 4.3, 4.5 and 4.7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	85, 103-104 and 120
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	As item 18
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see item 15).	---
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see item 16]).	---
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	119-121
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	121-122
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	122-123
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Not reported

Appendix Four: External facilitators' interview schedule

Welcome

- Introduce myself
- Confirm the project title is '*last year of life in nursing care homes study*'.
- Obtain written consent for the interview.
- Confirm that the interview can be discontinued at any time.

Background demographics

- Length of time they have been qualified as a nurse
- Where they undertook their nurse training
- Background in end-of-life care/palliative care/qualifications
- Grade/band of external facilitators post
- Full time/part time (hrs per week)
- Any other associated employment
- Previous experience of facilitation of the GSF or GSFCH
- Any roles in the past that they feel have enabled them to undertake the role of a GSFCH external facilitator
- Number of nursing care homes they facilitated

Background Information

- What does the term facilitation mean to them
- Was anyone other than them providing a role in the nursing care home that would have contributed to the GSFCH facilitation
- Talk a little about the nursing care home – context
 - Internal enablers/barriers
 - External enablers/barriers
 - Organisational enablers/barriers
 - Environmental/financial enablers/barriers

Explore their role as a facilitator

- Explore what level of facilitation were they able to offer to nursing care home (frequency of visits/contacts etc) and how this worked.
- Explore what they found positive about their role as an external facilitator
- Explore what was difficult about their role
- Explore what support they received whilst undertaking this role and their opinion
- Looking back would they have done anything differently
 - Explore their overall opinion of their role as an external facilitator and what they think may aid this role in future
 - What facilitation, if any, are they able to offer to the *Phase 6* nursing care home (frequency of visits/contacts etc) now.

At the end of the interview

- Ask if they can give a summary as to how facilitation of the GSFCH programme should be provided
- Summarise the experience they have shared to confirm a correct interpretation.
- Anything else they would like to say
- Thank them for taking time to participate in and share their views regarding their external facilitator experience.

Appendix Five: Nurse Managers' Questionnaire

Gold Standards Framework Care Home Evaluation

Nurse Managers' Questionnaire

8.5 Did you participate in the Nursing Home Managers' action learning sets that Jo Hockley held over 9 months at St Christopher's during 2009-2010?

Yes Go to Question 8.6

No Go to Question 8.7

8.6 How do you feel the action learning sets impacted on you being able to implement the GSFCH programme?

8.7 Did you, as the Nursing Care Home Manager, have an outside facilitator to help you implement the GSFCH programme?

Yes No

Please comment below (continue on an extra sheet of paper if necessary)

Appendix Six: GSFCH Coordinators' Questionnaire

I would be most grateful if you could complete the following questionnaire and return it to your nursing care home manager within the NEXT WEEK. I will be returning to the nursing home on to collect this questionnaire.

1. Please state the date that you become a GSFCH coordinator for the *Phase 6* GSFCH in this nursing care home?

2. Please *tick* the GSFCH workshops that you personally attended at St Christopher's Hospice.

Dates of the GSFCH Workshops	Workshop	Yes I did attend (tick)
September 2009	Workshop 1 – coding register and care matrix	
November 2009	Workshop 2 – advance care planning and symptom control	
February 2010	Workshop 3 – Support, bereavement care and care in final days	
May 2010	Workshop 4 – sustaining, embedding and accreditation	

3. In what ways have **you** personally gained from being a GSFCH coordinator for GSFCH programme in your nursing care home?

4. What things have been most difficult for **you** personally as a GSFCH coordinator? (*please list*)

- a.
- b.
- c.
- d.
- e.

5. Did your experience as a GSFCH coordinator compare with your initial expectations? (*please tick*)

Yes No

Please comment if you would like to:

6. What has helped you as a GSFCH coordinator to implement the GSFCH programme within your nursing care home? *(please list)*

7. Did you have access to local facilitation to assist you in your GSFCH coordinator role?

Yes *(please go to Question 8)*

No *(please go to Question 12)*

8. (a) *Who* provided this assistance/facilitation to you?

8. (b) In what way/s did they help you? *(please list)*

9. How often did you have contact with your external facilitator? *(state number of contacts)*

The number of **visits/training sessions** per month was

The number of **phone contacts** per month was

10. Was this level of facilitation sufficient?

No (*please go to Question 11*)

Yes (*please go to Question 14*)

11. (a) Can you describe what additional facilitation you felt you needed?

11. (b) How would this additional facilitation have benefitted you?

(Please go to Question 14)

12. Do you feel an external facilitator to the nursing care home would have assisted you in your GSFCH coordinator role?

Yes (*please go to Question 13*)

No (*please go to Question 14*)

13. Please explain why facilitation or assistance from an external facilitator would have assisted you in your GSFCH coordinator role?

14. Do you think end-of-life in your nursing care home has changed as a result of the GSFCH project? (*please tick*)

Yes

No

If 'no' what has prevented any change?

If 'yes' in what ways do you see changes?

15. (a) Please describe any gaps that *still* remain in the management of residents' end-of-life care in your nursing care home?

15. (b) Why do you think these gaps persist?

16. What will help you to sustain the changes you have made as a result of the GSFCH programme?

17. Please describe below any other comments you have regarding what it has been like to be a GSFCH coordinator?

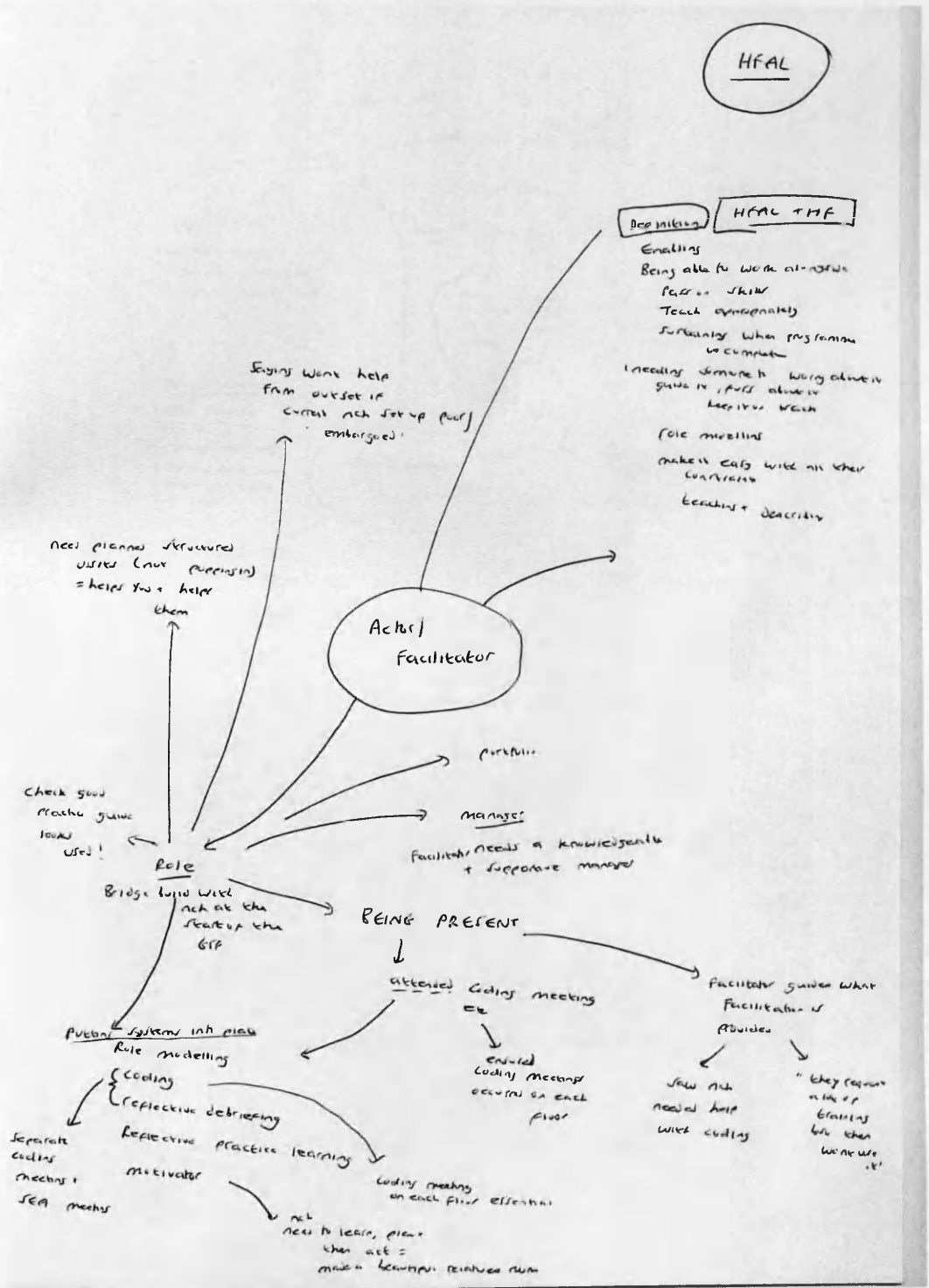
Thank you very much for completing this questionnaire. Please return it to your nursing care home manager in the sealed, labelled envelope.

If you have any further questions or need further information please contact:
[details provided]

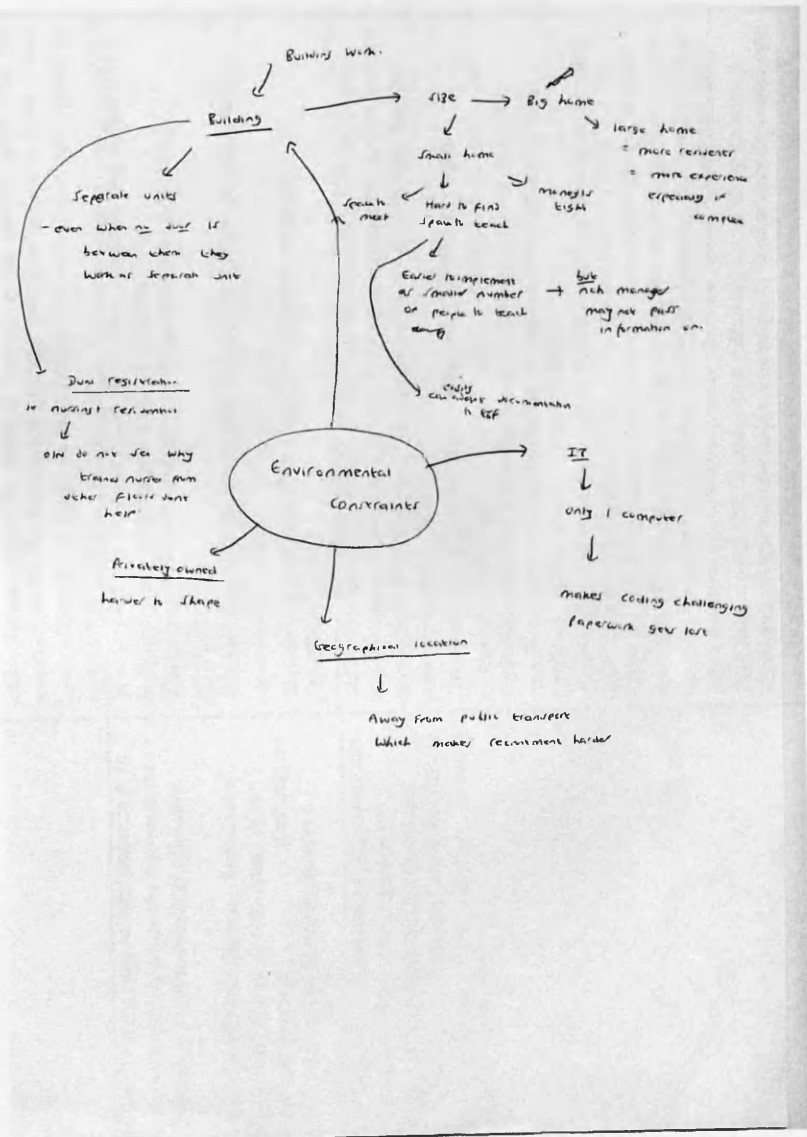
Appendix Seven: Summary record of the external Facilitators' Activity Log

Nursing care home code:	Year.....												
	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March	April	May	
Number of contacts													
- Email													
- Phone													
- Visits													
Total time spent													
Subjects													
Role modelling													
Group education in home													
Coding													
Significant Event Analysis/Reflection													
Meeting with GSFCH coordinators													
Meeting in home with nursing care home manager +/- GSFCH coordinators													
Network meetings													
After Death Analysis													
Cluster group meetings													
External meeting/training:-													
- GSFCH workshops (external facilitator)													
- MacPac training													
- Other													

Appendix Eight: Mind map – mapping ideas during initial reading of external facilitator interviews



Appendix Nine: Environmental constraints: mind map and associated template analysis showing factor/category and sub-themes



CATWOE Template: environmental constraints

Factor/ category	Sub-theme	Act as an enabler if they are in practice during implementation of the GSFCH Programme	Act as a barrier if they are not present in practice during implementation of the GSFCH Programme
Environmental constraints	Geographical location	<p><i>I think it seems to be more easy to implement in a, in smaller care environments, because the information can be spread amongst smaller amounts of people.... [F11]</i></p> <p><i>'It's a lovely home and I think the way, because its purpose built it's ideal. We've got the space to set things up to have the meetings And they've got space outside where they've made the erm remembrance garden.' [F15]</i></p>	<p><i>'I know that they do have a problem recruiting staff here as well because of the location, so geographically they're quite isolated and not on the normal, the treadmill of public transport.... So, erm... whereas, you know, other homes might be able to recruit quite quickly and then get somebody into the team quite quickly, get them settled in, here if they lose somebody, it tends to take longer to recruit and get somebody established.' [F13]</i></p>
	Size of the care home	<p><i>'In a large home, our is a 75 bedded one, it would be very difficult to co-ordinate the programme alone.' [C.NLF14.000]</i></p> <p><i>'Keeping up colour co-ordination - ? not vital in a small home' [C.NLF2.000]</i></p> <p><i>'It's my biggest home, erm, and it is hard work to get anything done consistently.' [F2]</i></p> <p><i>'Building of staff confidence due to infrequency of deaths.' [M.HF-ALS.002]</i></p>	<p><i>'As a coordinator for the GSFCH it was my remit to roll it out on the elderly mental health unit. This in itself was one issue but how to explain to residents who all have fairly advanced dementia and most have no mental capacity.' [C.NLF14.001]</i></p> <p><i>'Dual residential getting them interested. [M.HF-ALS.004]</i></p> <p><i>'I thought at the beginning of the course I would have the time to get GSF really embedded into the home, with being reduced in resident numbers due to rebuild, but did not anticipate how disruptive noisy building work would be.' [C.NLF9.000]</i></p> <p><i>'I think also because it's two separate units and they are run separately, and they are actually physically apart, has been quite difficult. [F8]</i></p> <p><i>'They're changing their identity but they're not able to change, they're not able to culturally change it, because their concept is so different and now they're suddenly, suddenly, being full blown nursing home and they can't, the transition's been too much for them I think. I think it'll take a long time, I think, for, to steer them, culturally to, to being a nursing home and a basic nursing home, you've got to look at nursing needs now.... I've got to get deeper than that and that's what I'm having trouble doing I think.' [F3]</i></p>
	Structure of the care home	<p><i>'I mean one of the good things that have happened, the whole place has been totally redecorated and it's absolutely stunningly beautiful now, so the actual environment is lovely to work in, erm, and I think that's boosted people, given them a little, you know, 'Actually, this is a fab place to work.' [F5]</i></p>	

Appendix Ten: Letter confirming ethical approval

12 May 2010

Study title: The effect of different models of facilitation when implementing the Gold Standards Framework in Care Homes (GSFCH) a cluster randomised control trial

REC reference: 09/H0715/74

Amendment number: AM01

Amendment date: 18 March 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 05 May 2010.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
CV -		18 March 2010
CV -		
NHS REC Form IRAS V 2.0	Lock code 19313/10697 9/1/159	19 March 2010
Notice of Substantial Amendment (non-CTIMPs)	1	18 March 2010
Covering Letter		06 April 2010

Membership of the Committee