Collaborative Research between Aston Research Centre for Healthy Ageing (ARCHA) and the ExtraCare Charitable Trust

Principal Investigator:
Carol Holland
Co-applicants:
Matthew Carter, Richard Cooke, Graham Leask, Rachael Powell, Rachel Shaw and Karen West
Research staff:
Danielle Clarkesmith, Jill Collins, Barbara Hagger, Amanda Kay, Jess Lambie, Leanne Liddell, and Stuart Wallis
Further Research Fellow Support (ARCHA fellow)
Alexis Boukouvalas

The final report

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Contents

A Longitudinal evaluation of the ExtraCare Approach

1.0 Introduction

This report consists of a summary of the full findings. Throughout the report the emphasis is on key learning points: what are the implications of the findings and what could be further developed?

ExtraCare management have contributed with a brief summary of their responses or plans to emphasise the collaborative nature of this project, to be found in Section 13.0 of the document. The full report pack consists of:

- This report
- A Framework synthesis examining common findings identified across different data types.
- A set of topic and factsheets that summarise findings in a transferable manner for use in presentations and discussions, both internally and with external bodies.
- A series of example outputs in the form of a portfolio pack
- Two tools:
    - a costing tool to enable ExtraCare to do the same costing for further residents as we have done for the sample. This needs Microsoft Access to work, but full instructions are given.
    - a Frailty tool – list of information needed to produce the frailty profile described. This is based on Microsoft Excel.
- Electronic versions of all items on a memory stick.

Original objectives: We set out with the overall objective of evaluating whether the ExtraCare approach gives positive outcomes for healthy ageing which result in measurable health and social care cost savings. In a longitudinal study, 162 new residents are compared against 39 control participants. We took measures of health, well-being, cognitive ability and mobility at entry, 3, 12 and 18 months. Qualitative data were gathered using focus groups, interviews and case studies. People were additionally invited to keep a diary to record activities. Outcomes also include health and social care usage and costs to contribute to answering the original question.

ExtraCare villages and schemes taking part: Fourteen Villages and Schemes took part in the project.

2.0 Numbers of people taking part

Initial targets for recruitment of 160 new residents and 25 control participants were slightly exceeded (162 and 33 respectively), although ExtraCare well-being data at baseline was only available for 151 of these. Over the centres used, 17% of new residents took part. By 18 months there were 108 ExtraCare and 29 control participants in the study for the Aston assessments (69 and 29 respectively for well-being data. The attrition is indicated by the difference between initial and final Aston assessments, whereas the difficulties in getting complete well-being (health) data are illustrated by the difference between the final Aston and final well-being data (108-69 = 39 missing well-being assessments). For the crucial 12 month health data (NHS or Care use are measured over 12 months) there are 96 ExtraCare residents (as against 127 residents in the Aston assessments, that is, 31 missing due to missing well-being assessments). There are 666 Aston assessments and 530 well-being assessments across the four time points. For qualitative data we conducted two or three focus groups at eight sites (total of 74 participants). We individually interviewed six residents within 2-5 months of moving into ExtraCare, then at 6 and 18 months after moving in. This was the only longitudinal component of the qualitative work. Three Case studies were conducted which included interviews and observation within the ExtraCare site. We

interviewed two managers formally and when on site met with managers and staff groups to discuss general issues.

Attrition: 40% of ExtraCare and 29% of Control participants left the study before completion. With our longitudinal design feature of periodically adding in new volunteers with matched duration of residence, this resulted in overall attrition of 29% (33.3% for residents, 6% for controls), comparing favourably with other similar studies. 33% attrition was anticipated in calculations of sample size. Attrition was selective to participants who were less well. Twelve ExtraCare volunteers died during the period (7.4%) and 14 stated their own or partner's illness as a reason for not continuing. One qualitative interview volunteer died between the second and third meeting. Those lost to sample were no older than those still available at 18 months.

Data summary and challenges: There were some challenges with the ExtraCare Well-being Advisors' data entry throughout the study which did eventually result in some loss of data, resulting in a mismatch between numbers with full Aston data and those with full well-being data, despite our best efforts and those of the Well-being Advisors. One of the most significant issues was gaps and changes in well-being staffing. Additional financial resources were authorised by ExtraCare to ensure that some of the missing assessments could be carried out where there was a longer term staffing vacancy. Nevertheless, there are still sufficient numbers for most of the analyses planned. ExtraCare was already planning a new centrally stored and more user-friendly data base, so any future data will be easier to use for all concerned.

Further description of initial sample: ExtraCare participants were significantly older than controls on average, had more chronic illnesses and differed in terms of socio-economic groupings such that there were fewer professional and higher management and more people with unskilled occupational backgrounds. Control group participants perceived their health to be significantly better than did ExtraCare participants at baseline, and had fewer care needs or functional limitations. Cognitive function and emotional well-being differed between the groups at baseline, even controlling for age differences. There were proportionately more men in the ExtraCare sample than in the Control sample (38.3% as compared with 25.8%).

3.0 Summary from the Diary data

57 ExtraCare and 22 control participants agreed at baseline to keep a diary of their activities over the period, down to 35 and 12 respectively by 18 months. Number of activities was categorised broadly into social, physical and intellectual activity types. There was significant increase in activities over the first 3 months in all categories, but then a levelling off or decrease. For the full duration, only social activity increase remained significant. Given our understanding of the benefits of physical, intellectual and social engagement, these findings indicate a need for continued efforts to involve people, support them to get involved, and listen to what they would like in terms of activities. At baseline, there were five people who reported no activities of any nature but there were none at any subsequent time period.

4.0 Summary from the Qualitative data

The aim of the qualitative arm of this study was to try to understand residents' perspectives and experiences of daily life in ExtraCare. We approached the data with openness and regarded participants as experts of their own experience. It is important to emphasise that whether residents' accounts of life in ExtraCare are 'true' or not, they are real to them and can tell us important things about perceptions and feelings. As well as gaining accounts from residents we also met with managers and conducted observations when visiting each of the eight sites in our sample.

Sample description: We aimed to gather data from a range of residents and staff. A total of 144 people (131 ExtraCare residents) took part in the qualitative components of the study. Of the

focus group resident participants, 83 were in villages and 48 in schemes. Of the six interview participants, three were in receipt of care or social support, one had private care, one was cared for by his wife, and one had no care. All reported at least one significant health concern.

Overview of findings: The focus groups generated some rich data around how ExtraCare had changed over time but also whether initial expectations were maintained. We focus on three areas which have shown to be consistent areas of concern to residents of ExtraCare taking part in focus groups and interviews:

1. **connectivity in and beyond ExtraCare**;
2. **perceptions of change in ExtraCare;**
3. **negotiating transitions and increasing needs.**

- Volunteering was experienced positively by some as a way of connecting to others in the ExtraCare community, or as a "new lease of life"; for some it was something they felt unable to do and therefore marginalised them from the 'able' residents.
- Some residents retained connections from the wider community and were able to maintain friendships; others struggled to meet people and felt lonely within the ExtraCare community.
- There was a feeling of change at ExtraCare among residents who had lived there a long time. Some of this was financial but other aspects were about a perceived culture shift in the organisation.
- Residents' sense of well-being may come from experiential activities, i.e. finding enjoyment in other people's activities or through reading or watching television.
- Domiciliary care provided can be experienced as a boost of independence to set one free to do activities one enjoys rather than worrying about the mundane activities of everyday life.
- Some residents expressed reticence to seek care perhaps through guilt around their own sense of duty to care for a spouse or through embarrassment or pride.
- Seeking care was perceived by some as letting go of one's independence.

Identity: There were less obvious subjective changes (or changes at the level of identity) in which residents sought to maintain inclusion in mainstream ExtraCare life and be seen as independent and self-sufficient, but were perhaps struggling to do so. This may not be consciously registered, but some perceptions of changes and decline in ExtraCare raised may relate to transitions in identity and subjectivity. However, in some locations during the period there were changes in provision of care due to Local Authority changing contracting arrangements. Some complaints may be well founded, of course, but there is also a need to listen to residents' complaints (against ExtraCare management and against other residents) as markers of difficult transitions, requiring emotional support.

5.0 Changes across time in the key psychological and functional measures

The most dramatic differences occurred in the early months after moving in, detailed in previous reports. Now there are data at four time points, we can use growth curve modelling to examine effects of time. The analyses employed a set of complex statistical controls for attrition, age differences and in some circumstances for ceiling effects (healthy people having no reported problems on some measures, e.g. Activities of Daily Living measures). As such, great care has been taken to ensure the reliability of findings.

Effects over time which were different to control group changes (that is, ExtraCare effects):
There were significant continuous improvements across the period in **depression, perceived health, memory and autobiographical memory,** in a way that was significantly different from the way the measure changed over time for the control group.

Positive Effects over time which were not significantly different from control group changes: *These are changes that we need to know about but which are not unique to ExtraCare residents.* This was the case for: **anxiety, communication limitations and fluency (executive function)**.

Variables which varied with age in the control group but not for the residents: This was the case for: **Instrumental Activities of Daily living (IADL) and Social Function limitations.** ExtraCare may be reducing the normally expected change in function with increasing age. This is also a feature of the fact that decisions to move into ExtraCare are usually needs related, rather than age related.

The two most important implications are that:

- some factors can be changed: decline is not inevitable and improvement is possible even in variables that commonly decline with increasing age, given a supportive environment;
- Age itself is less important than health in terms of determining need for support and potential decline

6.0 Well-being data

Comparisons here are focussed on Baseline to 12 month data.

Social care costs: 19% of the sample were in receipt of care at both time points. ExtraCare costs an average of £427.98 less per person per annum than comparative local authority charges. This difference is greater at higher levels of care, and varies according to local authority costs in each location. For the people who were in the sample **at both time points**, the difference reduced from £414.61 to £363.77. Savings for the more expensive levels of care increase over time.

NHS Costs – Comparing EC and Control Participants: Total NHS costs were estimated for each participant, including practice and district nurse, GP and outpatient appointments as well as admissions. Average ExtraCare resident NHS costs reduced by 47% over 12 months. Control NHS costs reduced by 14.1%. BUT when you control for the fact that the more poorly are the people who left the sample this is a 38% reduction, (still a significant reduction). This equates to an average saving of **£1114.94 per person per year**.

In using this figure to scale up for the whole population, it should be borne in mind that this is probably a maximum, e.g. we did not assess people who do not have capacity to consent, and we may surmise that many very poorly people do not take part at all. Costs for these people may not have shown reductions to the same extent.

Health profile
Medications, illnesses and lifestyle: ExtraCare participants took more prescribed medications than did controls and had a significantly greater number of chronic illnesses at baseline. However, this was related to the age difference in the samples, rather than any other difference between the groups. There were subtle differences in prevalence of specific co-morbidities, and the control group fared better throughout in terms of lifestyle factors (exercise, consumption of fruit and vegetables). Over the 18 month period, both groups showed improvements in blood pressure. There were reductions in BMI and Waist circumference between baseline and 18 months in ExtraCare residents while these remained unchanged in control group.

There was a significant initial increase in number of prescribed medications for the ExtraCare group perhaps as well-being support resulted in new diagnoses, but this then remained stable. A reduction in polypharmacy was anticipated, given the use of medication review, but this did not clearly occur. There was no significant change in number of co-morbidities.

Healthcare use: GP visits and ExtraCare drop-in clinics: After 12 months GP usage (planned) by ExtraCare residents in the sample had decreased by 46%. No such reduction was seen in

emergency appointment data. We investigated the hypothesis that this may be because residents use the well-being drop-in clinic as a substitute for booking routine GP appointments, given that well-being drop-in appointments steadily increased over the period. At baseline, number of drop-ins and number of planned GP visits was significantly positively correlated – the more a person visited their GP, the **more** they visited the drop-in clinic too. At 12 months, this relationship had gone completely. Drop-ins increased and GP visits reduced over time. Despite this, the relationship does not become negative which would have been definitive evidence that drop-ins are directly replacing GP visits. That is, it is not the case that the more a person visited the drop-in centre, the less they visited their GP. The change is not necessarily reflecting individual level changes, just in the group as a whole.

Planned and unplanned hospital admissions and length of stay: The average number of planned admissions to hospital reduced for ExtraCare participants by 12 months by 31% (no change for control participants). The large variance and small effect size means that this was NOT a statistically reliable change. Number of unplanned admissions did not change for either group.

Together, these findings support the Drop-in clinic model:
(i) Availability of local, accessible, relatively informal health support, particularly for ongoing day-to-day chronic illness care, that does not need an appointment (a drop-in service), can have a significant effect on reducing GP usage, giving potential cost savings.
(ii) Communities where homes are accessible, care support is readily available and existing care needs understood may result in reduced length of stays in hospital.

Duration of unplanned hospital stays: This reduced from a median of 5-7 days at baseline, to 1-2 days thereafter. This was not related to increase in number of Drop-ins.

7.0 Frailty
Frailty is defined as a state of high vulnerability for adverse health outcomes when exposed to a stressor, that is, an absence of resilience. Frailty is related to morbidity and mortality, and utilisation of healthcare. **Crucially, frailty, and especially pre-frail states, are <u>malleable.</u>**

The Frailty Profile: We constructed a frailty measure for this population at each assessment to compare longitudinally, using a frailty profile concept (Rockwood et al, 2006). People were categorised into **frail, pre-frail** and **not frail** based on published criteria.

ExtraCare residents were frailer than controls throughout. Initial improvements in frailty did not continue over the full period, although the initial improvements may have delayed decline. Nevertheless, a focus on interventions to prevent or reduce frailty could be further developed and evaluated using such an indicator.

Frail Participants: Of the 44 residents categorised as frail at baseline, 22 remained in the sample 18 months later, 14 (63.6%) remained categorised as frail with 8 returning to a pre-frail or not frail state. One control participant was categorised as frail at baseline, returning to a not frail state by 18 months.

Pre-frail residents: Given that the "pre-frail" is used to indicate people at risk of becoming frail, it is important to know if this occurred for ExtraCare residents. Of the 62 people designated as pre-frail at Baseline, 42 were still in the sample at 18 months and 8 (19%) had returned to a not frail state, with 4.7% being designated as frail at 12 months. Ten control participants were categorised as pre-frail at Baseline. Of the 8 remaining at 18 months, all were still in the same category.

Putting it together: Frailty and Costs. As indicated in Section 5, NHS costs in total reduced significantly. The reduction for the frail residents was the most striking: for those in the sample at

baseline and follow-up, this changed from an average of £3274.21to £1588.04 average per person. That is, a 51.5% drop. Use of this figure needs to bear in mind that the frailest within this group are those who have died or dropped out of the study.

Reductions in social care costs over time were much smaller (£2-300 per person on average). Care costs for frail participants are much higher than for pre-frail participants. A frail participant's average annual care costs were £4720.96 at the 12 month point, as compared to £61.40 for a pre-frail resident (given that most pre-frail residents are on zero care). **This underlines the importance of strategies to intervene in pre-frailty to reduce the likelihood of it becoming frail.**

Physical versus cognitive frailty: In order to determine the source of impacts more precisely, we produced a separate cognitive and physical frailty profile. The data showed that cognitive and physical frailty predict care level jumps from one level to the next differently, with cognitive frailty having a more even influence. The main predictor of higher levels was cognitive frailty (although modelling was not possible with the small numbers on care).

8.0 Modelling: What predicts change?

Which measures are useful for predicting decline in independence outcomes?
IADL: Change in ACE-R (overall cognitive function) and **change in frailty**: e.g. for every one point increase in ACE-R, it became less likely that IADL would decline. This did not differ by group.

Functional Limitations Profile: Baseline age and **increase in Depression**: e.g. for every one point increase in depressive symptoms, people were 1.36 times more likely to have increases in functional limitations.

A focus on rehabilitation and improvement of cognitive function and on treatment or prevention of depression will have important direct effects on independent function and quality of life, and therefore on need for further care and support.

Which measures are particularly useful for predicting Care level?
Care Level: Frailty, IADL and ADL (a more basic independence measure), and **ability to stand up from a chair** (time taken or inability). Given that IADL can be impacted by change in its underlying predictors, rehabilitative focus on these predictors would then have an impact on care needed.

However, **good linguistic ability** was also an important predictor of Care Level. Once frailty, IADL and ADL, and sit-to-stand was taken into account, **language had an opposite effect** – people with higher language ability were **more** likely to have higher care levels, suggesting that those who could communicate well and understand information may be more likely to get the care they need. **Poorer linguistic abilities seem to result in people being less likely to get care, even in the context of frailty.**

This has important implications for an advocacy role for frail people in helping them get the care they need. This issue reduces from Baseline onwards, validating ExtraCare's support, but it does still have an effect.

Which measures are particularly useful for predicting well-being outcomes?
The main predictor of improvement in depression, perceived health and autobiographical memory in the total sample is which group a person is in, the ExtraCare residents or the control group, whereby living in ExtraCare predicts improvements in these wellbeing measures.

Depression/mood improvement: change in cognitive function; **change in anxiety** e.g.an increase in anxiety of one point reduced the chance of mood improving (people were ¾ as likely to

improve on mood if their anxiety increased). **Number of chronic illnesses** was marginally significant (p<0.1) again reducing the chance of improvement in mood as numbers of illnesses increased and should also be borne in mind. Given that we generally an overall improvement in mood for ExtraCare residents (see other analyses), this analysis gives us indicators of which residents may be less likely to improve, and specifically highlights that people who are showing signs of anxiety are at risk.

And within cognitive sub-components? **Fluency, our indicator of executive function**: a one point increase in fluency increased the likelihood of improving in mood by 1.45 times.

Which measures are particularly useful for predicting frailty outcomes?
Frailty increase/no increase: change in autobiographical memory and change in ACE-R, an increase in each reducing the likelihood of frailty increase; **initial frailty** predicted lack of decline (people were only one third as likely to get worse if they were already frail).

This result implies that interventions aimed at maintaining and improving cognitive and socio-emotional measures of cognition where possible will have a positive impact on frailty change. This is in addition to the importance of changes in the underlying measures that make up the frailty profile, notably physical weakness, which can improve as a result of carefully designed exercise programmes.

Which measures are particularly useful for predicting NHS cost outcomes?
Using a linear regression procedure to determine the predictors of variance in amount of change in NHS costs from Baseline to 12 months, we could predict 56% of the variance in NHS cost change. The only predictor that made a significant impact individually was change in **Instrumental activities of daily living** (IADL). F**or every 1 point increase in IADL, there is a £2221 reduction in NHS costs** if all other variables are held constant (nothing else changes).

In terms of reducing NHS costs, it seems that an important focus is to improve Instrumental Activities of Daily Living, which our earlier analyses suggest are significantly impacted by change in depression and cognitive function. However, further analyses will be able to determine whether lifestyle changes such as physical activity, or other preventive activity has any further impact.

9.0 Benefits of further screening
The above analyses have all indicated benefits for screening measures that we added to the total screening that ExtraCare does. The recommendation is that Well-being Advisors consider the following variables as to whether they would be useful for identifying people who might be missing out on care they need or on other interventions that may reduce decline. The opposite is also the case – there may be people receiving support for issues they no longer have concerns with (e.g. depression that has been alleviated).

Frailty
The frailty profile we produced predicted 48% of the variance in care level (p<0.001). However, our data indicated a significant number of people categorised as frail who were not receiving care support. The low percentage of people designated as frail who were receiving formal care at 12 months (only 61% of them) underlines the need for regular screening of needs (although some may be getting care informally).

Depression
Well-being screening identifies people with a diagnosis of depression only, it does not perform standardised screening. There was a significant mismatch between those identified by our measure and those identified in well-being data as depressed. The percentage of unidentified people with probable depression reduced over the period from 68.8% to 46.7%, but further

screening to support these efforts is recommended. During the period covered by the study, people referred to the "Locksmiths" (support for people with cognitive impairment and mental health concerns) began to be screened using the Geriatric Depression Scale. This may be the source of the very positive reduction of unidentified people with probable depression, but the point at which screening is conducted could still usefully be discussed, with the numbers still being missed suggesting a benefit for population based screening, as opposed to only screening those referred.

Cognitive function
We used the overall ACE-R cut-off scores to indicate people with mild cognitive impairment and levels of performance indicative of possible dementia. We then compared those against numbers working with the "Locksmith".
Baseline: Of the 29 people with scores indicative of dementia, only 2 had a diagnosis on their well-being chart. Only 3 of the 29 were working with the locksmith.
12 months: Of the 17 with scores indicative of dementia, only 5 had a diagnosis of dementia and only 1 was working with the locksmith.

ExtraCare keeps separate data and screening measures on those referred to the locksmiths, but they were not available to the study, although we included data on "referred" even where this referral was refused in the above data. There may be some mismatch between the well-being and Locksmith data, supporting ExtraCare's current programme to improve the centrality of their data, but the same issue about standard population screening for risk is as valid for cognitive impairment as it is for depression above.

Summary
There are a lot of people who may benefit from specific support for cognitive impairment or depression who are not receiving it as far as we can tell. Screening for frailty, depression and cognitive impairment is recommended.
However, the data also confirm that people with other perceived difficulties than clear cognitive impairment are benefitting from the locksmith programme.

10.0 In depth analyses on specific issues
Autobiographical memory: Autobiographical memory test performance (AMT) consistently mediates between underlying cognition (in terms of executive function), and outcome perceived health. It also consistently mediates effects of depression on outcomes such as IADL.

Our modelling showed that both depression and AMT are working together to mediate the impact of executive function on functional limitations. If AMT is higher, then depression will have less of an influence and vice versa. That is, even in the context of changes in cognition and depression, if autobiographical memories can be recalled in a specific detailed manner, outcome functional limitations will be less affected. This effect was robust throughout the different assessments.

Mild Cognitive Impairment: Mild cognitive impairment (MCI) is considered to be a symptomatic pre-dementia phase of Alzheimer's Disease (AD) and is viewed as a transient and high risk phase. Interventions to promote improved well-being or cognitive functioning could be particularly pertinent for this group.

Residents with MCI were only marginally more likely to decline over the period than initially unimpaired participants. Indicators suggest some early benefits of living in ExtraCare for residents with MCI which may be delaying the decline that would put people into the possible dementia category, but also demonstrate that initial transitions are not maintained: more could be done to improve on-going support, although it is also recognised that not everyone who is offered this support will take it up.

Predicting Cognitive decline: The main significant contributor to the model was **change in depression score**. For every 1 point increase in depression score, people were 1.64 times more likely to show significant cognitive decline. **Note that this analysis excludes people in the dementia range at Baseline.**

Conclusions: Highlighted findings

Researchers and policy-makers have a limited understanding of the impact of innovative integrated housing, care and support models on the cost of care and support for older people. This 3 year longitudinal study sought to compare changes over time in care needs and care costs of new ExtraCare residents with those of a control sample in the community. It also sought to examine the effects of this integrated approach on perceived health and well-being, cognition, social functioning and independence over time.

Key findings

- The ExtraCare Charitable Trust model can result in significant savings for NHS budgets – over a 12 month period costs total NHS costs (including GP visits, practice and district nurse visits and hospital appointments and admissions) reduce by 38% for ExtraCare residents who were in the sample across the period.

- NHS costs for 'frail' residents had reduced by 51.5% after 12 months.

- Use of the ExtraCare Well-being Service, which provides accessible, relatively informal (drop-in) support, for preventative health-care and ongoing day-to-day chronic illness care increases over the period. At the same time (although not directly related on an individual level), there is a significant reduction in pressure on local GP surgeries, with a 46% reduction in residents' routine or regular GP appointments in year one, supporting the drop-in model.

- The ExtraCare model is associated with a significant reduction in the duration of unplanned hospital stays, from an average of 8-14 days to 1-2 days.

- The ExtraCare model is likely to offer significant potential savings in the cost of social care for local authority commissioners.

- The cost of providing lower level social care using the ExtraCare model was £1,222 less per person (17.8% less) per year than providing the same level of care in the wider community (on average, with variation by local authority) and the cost of higher level social care was £4,556 less (26% less) per person per year).

- Frailty, and especially pre-frail states are malleable - a significant number (19%) of ExtraCare residents designated as 'pre-frail' at baseline had returned to a 'resilient' state 18 months later.

- A frail person's average annual care costs were £4720.96 at the 12 month point, as compared to £61.40 for a pre-frail resident (most receiving no formal care), underlying the importance of preventative interventions to reduce the likelihood of a person becoming frail.

- At baseline new residents had more difficulties with cognitive functions, independence, health perceptions, depression and anxiety than controls, but after 3 months these differences have reduced and some have disappeared, with significant improvements in psychological well-being, memory and social interaction for ExtraCare residents.

- After 18 months ExtraCare residents in general showed a reduction in depression – and those with low mobility, showed the greatest improvement (from their lower initial levels). At the end of this period serious depression can no longer be predicted by a person's mobility; those whose mobility reduced over period did not generally become significantly more depressed, but the overall relationships between mood and mobility were maintained, suggesting positive findings, but still room for more to be done.

- Social interaction, for residents of ExtraCare, is not significantly related to mobility difficulties after 12-18 months of residence.

- The ExtraCare Charitable Trust model seems to 'level the playing field' by successfully removing differences in self-perceived health differences which are initially related to social class.

A Longitudinal evaluation of the ExtraCare Approach

1.0 Introduction

The full report consists of a pack which includes:

- this summary of the full findings
- a set of topic, or fact sheets that summarise findings in a transferable manner for use in presentations and discussions, both internally and with external bodies.
- a framework synthesis which combines the findings from the various streams of evidence and produces some overall conclusions.
- example outputs in the form of a portfolio of conference presentations (power point slides), conference posters, book chapters, responses to policy engagement requests, economic summary, and papers submitted for peer reviewed journal publications thus far
- The pack also includes two tools:

  (i) a costing tool to enable ExtraCare to do the same costing for further residents as we have done for the sample. This needs Microsoft Access to work, but full instructions are given.

  (ii) A Frailty tool – list of information needed to produce the frailty profile described. This is based on Microsoft Excel.

Journal publication work will continue for at least 12 months as publishing in such formats has a long timeline.

Throughout the report the emphasis is on key learning points: what are the implications of the findings and what could be further developed? ExtraCare management have contributed with a brief summary of their responses or plans to emphasise the collaborative nature of this project and its direct impact on the charitable trust (Section 13).

1.1 Original objectives

We set out with the overall objective of evaluating whether the ExtraCare approach gives positive outcomes for healthy ageing which result in measurable care cost savings. In a longitudinal study, 162 new residents were compared against 39 control participants. We took measures of health, well-being, cognitive ability and mobility at entry, 3, 12 and 18 months. Qualitative data were gathered using focus groups, interviews and case studies. People were additionally invited to keep a diary to record activities. Outcomes also include health and social care usage and costs to contribute to answering the original question.

1.2 ExtraCare villages and schemes taking part

We began with eight schemes and villages. Because of lower turnover than anticipated and ExtraCare well-being staffing changes, recruitment to target sample was difficult and so five further centres were added, enabling full recruitment.

1.3 Data summary and challenges

ExtraCare well-being and Aston assessment databases were merged to enable the final analyses across the data. Challenges with the ExtraCare Well-being Advisors' data entry have been significant all along and did eventually result in some loss of data, resulting in a mismatch

between numbers with full Aston data and those with full well-being data, despite our best efforts and those of the Well-being Advisors. One of the most significant issues was gaps and changes in well-being staffing. Additional financial resources were authorised by ExtraCare to ensure that some of the missing assessments could be carried out where there was a longer term staffing vacancy. Nevertheless, there are still sufficient numbers for most of the analyses planned. ExtraCare was already planning a new centrally stored and more user-friendly well-being data base, so any future data will be easier to use for all concerned.

1.4 Learning point

> **Aston:** The plan to use ExtraCare well-being data was suggested to us to make good use of this data already collected. However, relying on the presence and uniform data entry of a wide range of staff, without specific research training to collect research quality data may not have been the best plan – collecting it ourselves when we did the other checks would have worked better.
>
> **ExtraCare:** We are already in the process of creating a new more user friendly database, one which has basic information saved so we don't need to keep asking the same things which won't have changed, and one which is better set up to prevent as many errors as possible. This was not linked to this research, but was already on our horizons to complete following feedback from the Well-being Advisors.
>
> A database which is centrally stored and does not require work to integrate from the different centres would save us all a lot of time!

2.0 Numbers of people taking part

At the start of the study, our target for recruitment was 160 ExtraCare and 25 control participants who enter the study at its start (baseline), and an additional 10 ExtraCare and 5 control participants who enter the study at each subsequent stage to support control for attrition and practice effects (although further attrition was still expected), see Table 1.

Table 1: Original design of the quantitative component of the study.

Baseline	3 months	12 months	18 months
160 ExtraCare (EC) **25 Controls**	⟶	⟶	⟶
Added participants for partial control of attrition (anticipated attrition 33% per 12 months)	10 new EC 5 new controls	⟶	⟶
		10 new EC 5 new controls	⟶
			10 new EC 5 new controls

For the Aston Quantitative Measures (the data gathered by Aston assessment visits) we achieved a final sample of 162 ExtraCare and 33 Control participants at Baseline. Overall population data provided by ExtraCare for the villages and schemes in the study indicated that 17% of new residents took part. By 18 months there were 108 ExtraCare and 29 control participants. That is, in total, we took 666 assessments across the four time points (Table 2). During the final year, we took the decision, in consultation with ExtraCare , to make the final assessment at 15 months for some people, given their late recruitment and the planned end of the funded period.

Table 2. Achieved sample: 1: Aston assessments

	Baseline	3 months	12 months	15/18 months
ExtraCare **Control**	162 31	134 (82.7%) 30 (96.8%)	111 (68.5%) 26 (83.9%)	97 (59.9%) 22 (70.9%)
Added participants for Partial control of Attrition (Anticipated 33% per 12 months)		10 EC 2 Control	6 EC 1 Control	2 EC 1 Control
			10 EC 6 Control	8 EC 6 Control
				2 EC 0 Control
Total sample				
ExtraCare	162	144	127	108
Control	31	32	33	29
Grand total	**193**	**176**	**160**	**137 (70.9%)**

For the well-being data collected and entered by the nurses there are 152 ExtraCare and 33 control participant assessments at Baseline (control well-being assessments completed by Aston staff) and 69 ExtraCare and 29 control participant assessments at 18 months, described in Table 3. For the crucial 12 month health data (health measures such as NHS or Care use are measured over 12 months) there are 96 ExtraCare residents. In total there are 530 assessments across the four time points.

Initial power analysis was conducted to determine sufficient sample size for the planned analyses, based on an example regression analysis with power of 0.80, effect size of 0.20, alpha level of 0.05, and anticipated maximum 13 predictor variables gave sample size of 101. We anticipated 30-33% attrition per 12 months. Given that our sample size for the modelling in which full health data was used was 96 (12 month data), we did not use as many as 13 predictors in any calculations. However, for the full data set (where modelling is based on Aston assessments or initial health status such as initial chronic illness diagnosis) we could have used more predictors, but in practice, we did not need to use that many. We could not do the full growth modelling on any data from the well-being source because a) much of it was only available at two time points and at least four are needed for this type of analysis (baseline and 12 months) and b) there were not enough participants at 18 months. We could, however, complete this for measures assessed using the Aston data. Where growth modelling was not possible, we used within participants

Analysis of Variance, or ANOVA, which can be conducted with as few as 24 participants for the same power.

Table 3: Achieved sample: 2. Well-being data
(ExtraCare well-being largely collected by well-being staff, control data collected by Aston

	Baseline	3 months	12 months	15/18 months
ExtraCare	151	87	91	65
Control	31	31	24	22
Added participants for Partial control of Attrition (Anticipated 33% per 12 months)		4 EC 0 Control	4 EC 6 Control	1EC 1 Control
			1 EC 0 Control	1 EC 1 Control
				2 EC 0 Control
Total sample				
ExtraCare	151	91	96	65 (45.7%)
Control	33	31	31	29 (84.8%)
Grand total	184	122	127	97 (52.7%)

For the full description of the initial sample, for example, recruitment by specific village or scheme, please see previous reports.

For the qualitative data, we conducted two or three focus groups at fourteen sites plus with controls, a total of 144 participants. We individually interviewed six residents within 2-5 months of moving into ExtraCare (T1), around 6 months later (T2) and then at 18 months (T3) since moving in. Three Case studies were conducted which included in-depth individual interviews and observation within the ExtraCare site. General observations at participating ExtraCare sites were also conducted during which time residents' movements around the communal areas (café, hairdressers, gyms, shops), environmental issues (noticeboards, TV screens, reception activity, visitors etc.), and general activity were noted. We interviewed two managers formally and when on site gathering other data met with managers and other staff groups to discuss general issues. Only one element of the qualitative work was longitudinal (the six interviews with residents); only one person did not complete the three interviews due to death following the second meeting.

2.1 Attrition

A total of 40% of ExtraCare study participants left the study before completion, and 29% of Control participants. With our longitudinal design feature of adding in new volunteers with matched duration of residence at each period, this resulted in overall attrition of 29%, with 33.3% for residents and 6% for controls. This compares favourably with other studies with similar samples. 33% attrition was anticipated in our calculations of sample size.

A concern with all longitudinal studies is that attrition will be selective to participants who are less well, leaving a less representative sample. Twelve of the ExtraCare volunteers died during the

period (7.4%) and a further 14 stated their own or their partners illness as a reason for not continuing. Fifteen withdrew saying they found the assessments too much or were anxious about them, 12 did not respond to contacts or withdrew without giving a reason (participants were informed that they did not have to give a reason for withdrawing). Two people moved out of the village, and six said they were no longer interested. One was not assessed further because of concerns about capacity to understand the consent. Of the control participants, none had died to our knowledge, but 5 could not be contacted.

Our previous finding that those who withdrew or were lost to the sample had poorer initial self-perceived health (see previous annual reports) was confirmed in the final dataset with a highly statistically significant difference (see Figure 1). This was mirrored in an objective measure of health, total number of chronic illnesses, with those lost to the sample having more chronic health diagnoses. It was also confirmed that people lost to the sample had lower scores on initial cognitive function scores, confirming the suggestion that those lost to the sample were less well and were experiencing lower functioning (see Figure 1). However, they were no older than those who stayed in the sample.

| t(191)= -3.38,p<.001; | t(189)=-2.71, p<.01 | t(182)=3.69, p<.001 |
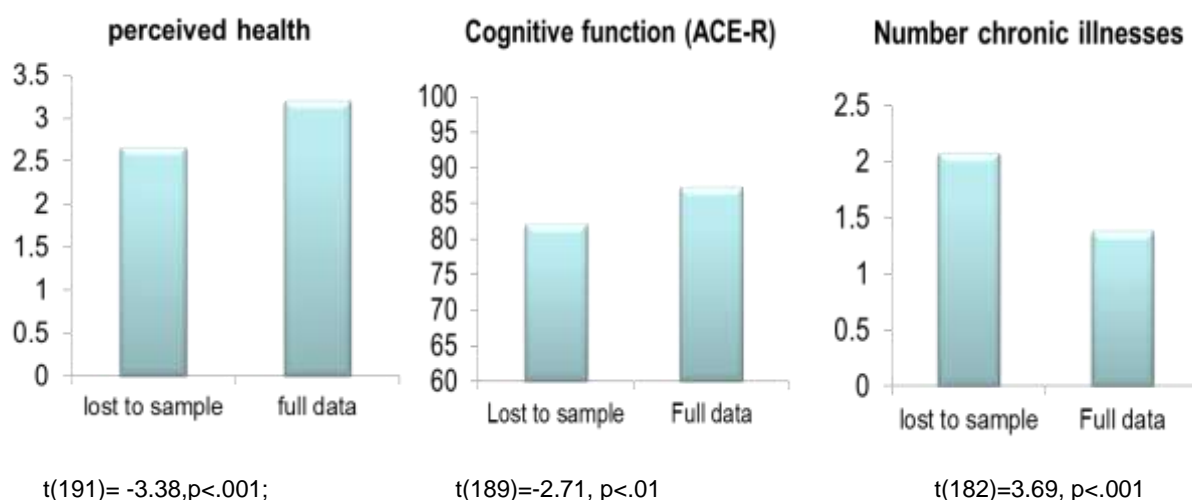
Figure 1: Differences between those who were lost to the sample and those remaining in three key areas, with statistical comparison.

2.2 Further description of initial sample details

Although similar, there are some important differences between the ExtraCare and Control groups. In summary, ExtraCare participants are significantly older on average, had more chronic illnesses and on average differed in terms of socio-economic group such that there were fewer professional and higher management and more unskilled occupational backgrounds. Control group participants perceived their health to be significantly better than did ExtraCare participants at baseline, and they had fewer care needs or functional limitations. Cognitive function and emotional well-being differs between the groups at baseline, even when controlling for age differences. There are proportionately more men in the ExtraCare sample than in the Control sample (38.3% as compared with 25.8%).

3.0 Summary from the Diary data

Overall, 57 ExtraCare and 22 control participants agreed at baseline to keep a diary of their activities over the period, with 60 and 17 respectively doing this at 12 months, and 35 and 12 at 18 months. Number of activities was categorised broadly into social, physical and intellectual activity types. How often people are involved in each type of activity varied widely, from 0 to 26 times a week. Using repeated measures analyses, for residents (blue lines), there was a significant increase in activities over the first 3 months in all categories, but then a levelling off or decrease. For control participants (green lines), number of activities was higher initially for all categories, and physical activity continued to increase over the period. Intellectual and social activities changed little in total. At baseline, there were five people who reported no activities of any nature but this is not the case at any subsequent time period, with the fewest activities reported becoming 2. Twelve (21.1%) of the ExtraCare participants reported no physical activity at baseline and 18 (31.6%) reported no intellectual activity, with 5 (8.8%) reporting no social activity. The increase in activity over the first 12 months was significant for social activities and marginally so for physical activities, but not so for intellectual activities. However, for the full four time points, only social activity increase remained significant. This is illustrated in Figure 2 and explored in more depth in Factsheets 3 and 4.

Activities:

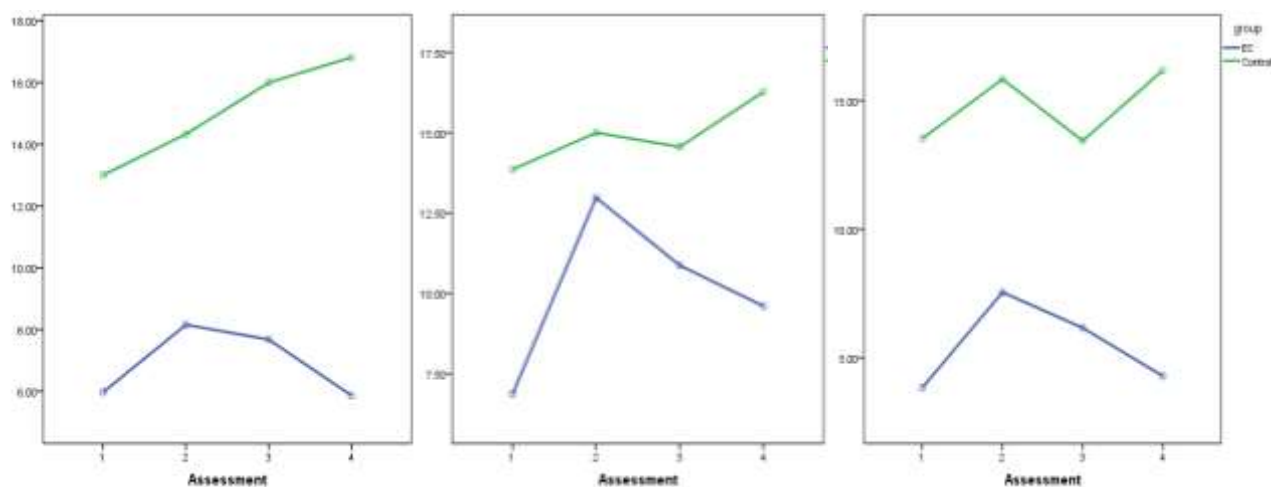### Physical   Social   Intellectual

Figure 2: Activity as it varied across the four time points (Baseline, 3, 12 and 18 months). A clear initial "honeymoon" effect is apparent.

> It is natural to expect some drop off after the first 3 months, once people have tried a variety of activities and discovered which ones they enjoy. However, given our understanding of the benefits of physical, intellectual and social engagement, these findings may also indicate a need for continued efforts to involve people, support them to get involved where they may not have had to try things on their own for many years, and listen to what they would like in terms of activities.

4.0 Summary from the Qualitative data

The aim of the qualitative arm of this study was to go beyond the "taken for granted" to try to understand the residents' perspectives and experiences of daily life in ExtraCare. We approached the data with openness and regarded participants as experts of their own experience. It is important to emphasise that whether residents' accounts of life in ExtraCare are 'true' or not, they are real to them and can tell us important things about perceptions and feelings. As described above, as well as gaining accounts from residents we also met with managers and conducted observations when visiting each of the eight sites in our sample.

4.1 Sample description

When recruiting participants we aimed to gather data from a range of residents. In the focus groups we were interested to explore any differences between those who had lived in ExtraCare for several years and those who had just moved in. This generated some rich data around how ExtraCare had changed over time but also whether initial expectations were maintained. See Table 4 for an overall summary of participants.

Table 4: Summary of ExtraCare qualitative data collection

	Scheme	Village	Total
Focus groups	48	83	131
Individual interviews (x3 where possible)	3	3	6
Case studies	1	3	4
Manager interviews	1	1	2
Observations	4	4	8

Further details of participants in the main components of the qualitative work are provided in Tables 5-6.

Table 5: Qualitative data groups

ExtraCare Study: total 131 residents					
Focus Groups (n = 123*)		**Interviews and Case Studies and shadowing (n = 13*)**		**Gender**	**Age -years**
7 schemes	9 groups (46 participants)	3 schemes	12 interviews	14 male	**62 to 91**
				36 female	**63 to 98**
7 villages	15 groups (77 Participants)	5 villages	17 interviews	39 male	**58 to 84**
				52 female	**60 to 93**
Total	24 groups		29 interviews	*** 54 residents took part in both focus groups and interviews/case studies/shadowing or more than one focus group** **** includes additional interviews with staff, not in demographic analysis**	
	59 hrs data collected from ExtraCare participants				

Table 6: Interview participants

Pseudonym (Gender)	YOB	Ethnicity	Marital status	Time at ExtraCare (at T1)	Site	Diagnoses (reported)	Services received (reported)
Annie (F)	1949	White British	Divorced	4 months	Village	Arthritis, respiratory condition	Private care
Clive (M)	1930	White British	Widowed	2 months	Scheme	Arthritis, AMD	Care level 2, social support
Derek (M)	1932	White British	Divorced	5 months	Scheme	AMD	Social support
Edgar (M)	1931	White British	Married	5 months	Village	Stroke	Cared for by wife (Eleanor)
Eleanor (F)	1935	White British	Married	5 months	Village	Chronic pain	None
Martha (F)[1]	1930	White British	Widowed	2 months	Scheme	COPD	Care level 5, social support

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[1] Martha died before the third interview; all other residents were interviewed three times (T1 2-5 months of moving in; 6 months later; 18 months after moving in).

4.2 Overview of findings

We focus on three areas which have shown to be consistent themes to residents of ExtraCare taking part in focus groups and interviews: connectivity in and beyond ExtraCare; perceptions of change in ExtraCare; negotiating transitions and increasing needs.

4.2.1 Connectivity in and beyond ExtraCare

ExtraCare offers residents opportunities to volunteer and to participate in a variety of physical and social activities. Many residents reported that these enabled them to be part of a community and for some, who had been isolated in independent community living, these quite literally had offered a new lease life.

Residents reported that volunteering had enabled them to make friends and to feel like valued members of the community. At the same time, some residents said that they could sometimes feel that expectations of volunteers were too great and had become wary of volunteering. Some residents felt that they had been burdened with caring responsibilities prior to moving to ExtraCare and now wanted simply to enjoy their lives. Some felt that where there were insufficient numbers of fit and able residents, expectations of those who were able to volunteer could be too great.

Others reported having some difficulty establishing friendships and getting involved in communal ExtraCare life on moving in to ExtraCare. Some residents also told us that for a variety of reasons, for example fluctuating or unpredictable health or extreme shyness, that they would prefer a social life that revolved around smaller groups within streets or apartments, but could not see a way to facilitate this. In general, the residents we spoke to tended to be the residents who are already active in ExtraCare life and who find it relatively easy to participate in events like focus groups. However, we also frequently heard from residents about other residents who are less likely to, or who never, participate in organised events. In the smaller schemes, in particular, active residents were concerned about what the withdrawal of frailer and older residents and, therefore, falling levels of participation in events, might mean for them.

So far as connections beyond ExtraCare are concerned, some residents maintain connections to and enjoy a social life within the local external community. The freedom to come and go is a highly valued feature of ExtraCare life. However, while some ExtraCare locations have excellent connections to local shops and the town centre, some are rather more isolated. How to manage shopping was a frequently raised concern among residents in focus groups. Most locations stock basic provisions, but when it comes to things like birthday presents, clothing or non-essentials, residents in some location were reliant on neighbours, taxis or family members. Some residents also said that they would like more organised outings and, in the schemes in particular, some residents expressed the view that these were less frequent than they used to be. This we also take up in the next theme of 'perceptions of change in ExtraCare'.

4.2.2 Perceptions of change in ExtraCare

Throughout the focus groups, in particular, we came across a perception among residents of recent changes in ExtraCare, which, to some extent, is supported also by comments from ExtraCare staff. Several concerns come under this broader heading:

• A perception that charges had been introduced for services and facilities that were once free of charge. Charges for apartment maintenance jobs like changing lightbulbs were frequently mentioned and for cups of tea and coffee and village and scheme events.

• A perception that charges for care had gone up or that what was once just regarded as a helping hand was now charged for as formal care.

• A perception that health and safety regulations were preventing residents from organising their own activities or were preventing them from helping each other.

• A perception that day trips and short breaks were less frequent or more expensive or that as residents became less mobile that they were more difficult to organise and/or had become more expensive as carers were now required to attend too.

• A perception that there is now insufficient replacement of frail residents with fit residents.[2]

These were accompanied by a more general perception of a change of culture in ExtraCare, expressed in phrases like 'things aren't what they used to be'; 'the atmosphere's not the same' and so on. Among staff too, we heard about changes at senior management level leading to new business management practices, but coupled with an acknowledgement that things also needed to change.

We have taken up these issues at length elsewhere (see especially West *et al*, submission to *Ageing and Society*), but we would argue that even if residents' perceptions of change are false in relation to 'the facts' they are worth taking seriously as they may be indicative of change at a more personal level as residents 'age in place'. This links very much with the theme of negotiating transitions and increased need that we take up next.

4.2.3 Negotiating transitions and increased need

What was apparent from interview data was how quickly physical needs can change. For three interviewees, Annie, Derek, and Clive physical needs had changed within twelve months (T2). Annie had lived with chronic pain and decreased mobility most of her life but had anticipated a decline which led to her decision to move into an ExtraCare village. At T1 she was still going out to meet with friends, could drive herself around, and travel by train. At T2 she had started to do less of these things but at T3 she was concerned about the speed of her decline. Annie received help privately but was beginning to consider seeking care from ExtraCare. She talked of feeling "at a crossroads" and "fiercely" wanted to retain her independence. However, a recent illness had left her chair-ridden which had frightened her into thinking that she may become housebound and require more "invasive" care than she was used to. Despite anticipating the need for care, and its availability on site, Annie was reticent about taking it up.

Derek and Clive both lived in schemes. Derek was not in receipt of care but Clive reported receiving a level 2 care package. Clive was hospitalised prior to living in an ExtraCare scheme and

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[2] On speaking with managers we were told that residents in receipt of care are required in order for them to receive funding for care provision which enables provision of a 24 hour staff model onsite. However, from the residents' perspective, they preferred to see frail residents replaced with fit ones so that the population did not continue to age and that aspects of the ExtraCare community, such as volunteering, could continue to support the lifestyle choice made.

on moving in showed great improvement in his mobility. However, by T2 he described himself as going "from a strong man to a nothing"; he went on to provide powerful imagery about the weakness he felt in his body: "you know the old tripe they used to have hanging in the butchers shops? My arm drops like that … my legs are skinny". Although Clive received help with his medication he spoke quite proudly of being able to manage his ADL although by T3 he was evidently weaker still and could have benefited from a higher care package. Derek did not receive any support but experienced a significant deterioration in his sight (through age-related macular degeneration) at each interview. (Increases in care level are not the gift of ExtraCare but require the Local Authority to approve increases in care packages). However, Derek was able to almost offset the negative he felt due to his bodily deterioration with a fascination for meeting new people and learning about his new world, as an older adult living alongside others with cognitive and physical problems. Derek had travelled with his work and enjoyed exploring new places and people; his intrigue in others had been maintained and he was keen to learn new things.

Eleanor and Edgar moved into an ExtraCare village year following Edgar's stroke. Prior to moving in, Eleanor had cared for Edgar at home and thus lost all connections to her previously busy social world. On moving into ExtraCare Eleanor began to take up activities she had done before and was thoroughly enjoying her new freedom. It was freedom within the constraints of being Edgar's carer. They received no care for Edgar from ExtraCare or elsewhere as Eleanor felt a strong sense of duty to do it herself. This meant she was unable to go out on day trips for fear of leaving Edgar alone, which in practice meant, she never left the ExtraCare grounds. When caring for Edgar at home, Eleanor described herself and "a caged bird". At T2 and T3 (over the first 18 months of living in ExtraCare) Eleanor's frustration began to become apparent: "I've got get out in the fresh air – out"; "I would like just one more cruise". Despite this frustration Eleanor was uncertain about seeking care for Edgar. She was worried he wouldn't like it but moreover she would feel guilty if someone else were to do it. This is particularly poignant because in Edgar's account it was clear that he had accepted his circumstances and was content to live vicariously through others or to gain satisfaction through his imagination in reading. The couple were at odds with each other; Eleanor wanted more life and opportunity while Edgar showed a readiness for death.

The final interviewee was Martha who illustrated a key benefit of receiving care. Martha lived in a scheme with a level 5 care package; she required oxygen and a wheelchair to get around. Her world had already shrunk to the ExtraCare community and building in which she lived but she was content with this. She described the care she received as a mechanism to set her free to do the things she enjoyed without worrying about looking after her ADL: "you've got a life in here, whereas at home you haven't". Martha felt secure because "there's always somebody at the other end of that [emergency] cord" and felt respected by the carers. Given her physical condition, Martha's level of well-being was surprising but her account could be used as an indication to others that receiving care could be construed as a facilitator to retaining independence rather than 'admitting defeat', as in Annie's and Eleanor's case. (These findings are explored in more depth in Shaw et al. in preparation.)

Our analysis and interpretation of the focus group data has also led us to what appear to be less obvious subjective changes (or changes at the level of identity) in which residents seek to maintain inclusion in mainstream ExtraCare life and to be seen as independent and self-sufficient, but are perhaps struggling to do so. This may not even be consciously registered, but we think that some of the perceptions of changes and decline in ExtraCare outlined above may actually

relate to these transitions in identity and subjectivity.   Some complaints may be well founded, of course, for example, given changes in Government policy regarding the funding of care packages, but we suggest that there is also a need to listen to residents' complaints (against ExtraCare management and against other residents) as markers of difficult transitions, requiring emotional support.

4.3 Learning point

- Volunteering was experienced positively by some as a way of connecting to others in the ExtraCare community; for some it was something they felt unable to do and therefore marginalised them from the 'able' residents.
- Some residents at some sites retained connections from the wider community and were able to maintain friendships; others struggled to meet people and felt lonely within the ExtraCare community.
- There was a feeling of change at ExtraCare among residents who had lived there a long time. Some of this was financial but other aspects were about a perceived culture shift in the organisation.
- Residents' sense of well-being may come from experiential activities, i.e. finding enjoyment in other people's activities or through reading or watching television.
- Care can be experienced as a boost of independence to set one free to do activities one enjoys rather than worrying about the mundane activities of everyday life.
- Some residents expressed reticence to seek care perhaps through guilt around their own sense of duty to care for a spouse or through embarrassment or pride.
- Seeking care was perceived by some as letting go of one's independence.

5.0 Changes across time in the key psychological and functional measures.

Initial changes from moving in to the first three months have been described in detail in the previous report and in a paper now submitted for publication (see portfolio, Holland et al, submitted). There were several very positive changes but the full data now enables us to see where there were significant changes over time generally for the ExtraCare residents, and also whether the way they changed over time differed from the way the control sample changed.

Having data at four time points means that we can use growth curve modelling to examine effects of time. The advantage of this is that it compares levels overall at each time over the whole population, as opposed to levels only for those for whom we have data at every time point, which is a limitation of other analyses for our purposes. The advantage of this is that it controls for some of the attrition effects, and also enables inclusion of people added in at the later stages who have lived in ExtraCare for the right duration but who do not have earlier measures. This is a useful technique to at least partially control for the fact that those we lose from a sample are usually the frailer.

The analyses thus employed a set of complex statistical controls for attrition, age differences and in some circumstances for ceiling effects (healthy people having no reported problems on some measures, e.g. Activities of Daily Living measures). Growth curve modelling with occasional use of Tobit modelling is used. As such, great care has been taken to ensure the reliability of findings.

5.1 Effects over time which were different to control group changes (that is, ExtraCare effects)
There were significant continuous improvements in some measures. That is, in addition to initial improvement, there was a linear effect of time such that the measure continued to improve throughout the time line, and this was significantly different from the way the measure changed over time for the control group.
This was the case for **depression, perceived health, memory and autobiographical memory**.

5.2 Positive Effects over time which were not significantly different from control group changes
These are changes that we need to know about but which are not unique to Extracare residents.
This was the case for: **anxiety, communication limitations and fluency (executive function**).

5.3 Variables which varied with age in the control group but which did not vary with age for the residents.
This is an important analysis because it demonstrates that ExtraCare may be reducing the normally expected reductions in function with increasing age. It is also a feature of the fact that people with some impairments or concerns move into ExtraCare rather than there being a specific age at which people decide to move (needs related, rather than age related).

This was the case for: **Instrumental Activities of Daily living (IADL) and for social function limitations.**
Some of these variables are analysed in more detail in Section 7 below.

The two most important implications are that:
(i)   some factors can be changed: decline is not inevitable and improvement is possible even in variables that commonly decline with increasing age, given a supportive environment;
(ii)   Age itself is less important than health in terms of determining need for support and potential decline

6.0 Well-being data

6.1 Sample description

As indicated above, the well-being data were not quite as complete as the Aston assessment data. However, a large amount of health and care data were available from a total of 537 entered well-being assessments. This data can be examined for a different set of demographic, health and care needs indications to the data above. For example, it revealed that all but 7 of those who gave ethnic group information identified themselves as white British.

Our comparisons here were focussed on baseline to 12 month comparisons because many of the measures use a 12 month timeline (e.g. number of hospital admissions in last 12 months).

None of the control group were receiving any formal care, but 29 of the ExtraCare group are receiving care across Levels 1 to 5 at baseline (19%), with 1 person receiving care at Level 5, and 11 at Level 4. At 12 months, total receiving care had changed little percentage wise, with 19.4% of the sample receiving care.

6.2 Social care costs

On average, based on baseline figures, across the care levels, ExtraCare cost £427.98 less per annum for the study participants than it would have done outside of ExtraCare in the wider community. This difference is greater at higher levels of care, and varies according to local authority costs in each location. This is illustrated in Table 7. This compares Local Authority (LA) with ExtraCare (EC) social care cost by level of care at baseline.

Table 7: Estimated Yearly Social Care Costs by Level of Care.

Level of care was converted into the number of hours (median) that they were likely to receive each week, this was then scaled up to give a yearly number of hours.

Care Level	LA cost	EC Cost	Difference (LA minus EC)
Level 1	1515.80	1247.00	368.80
Level 2	6878.00	5656.00	1222.00
Level 3	10722.25	9910.75	811.50
Level 4	17497.60	12941.40	4556.20
Level 5	23676.00	19750.50	3925.34
No care	0.00	0.00	0.00
Average difference			427.98

N.B. The average difference per person per year includes the large number of people who receive no care.

For the people who were in the sample **at both time points**, the difference reduced from £414.61 to £363.77 (marginal effect, p=.06).

The interaction between level and time was significant: the difference **increased** for Levels 2, 4 and 5, and **reduced** for Level 1. That is, the savings for the more expensive levels of care are increasing.

6.3 NHS Costs – Comparing ExtraCare and Control Participants

Total NHS costs were estimated for each participant, including practice and district nurse, GP and outpatient appointments as well as admissions. Average ExtraCare NHS costs reduced by 47% over 12 months. This is a highly significant effect, p<0.001. Control NHS costs reduced by 14.1% BUT when you control for the fact that the more poorly are the people who left the sample (dashed lines in Figure 3), this is only a 38% reduction, but still significant, p<.05. This equates to an average saving of **£1114.94 per person per year,** illustrated in Figure 3.

Scaling up from this to an estimated ExtraCare population of 5,000, this is **£5.57 million per annum**, although this is probably a maximum, e.g. as we don't assess people who do not have capacity to consent, and we may surmise that many very poorly people do not take part at all. That is, costs for these people may not have shown reductions to the same extent.
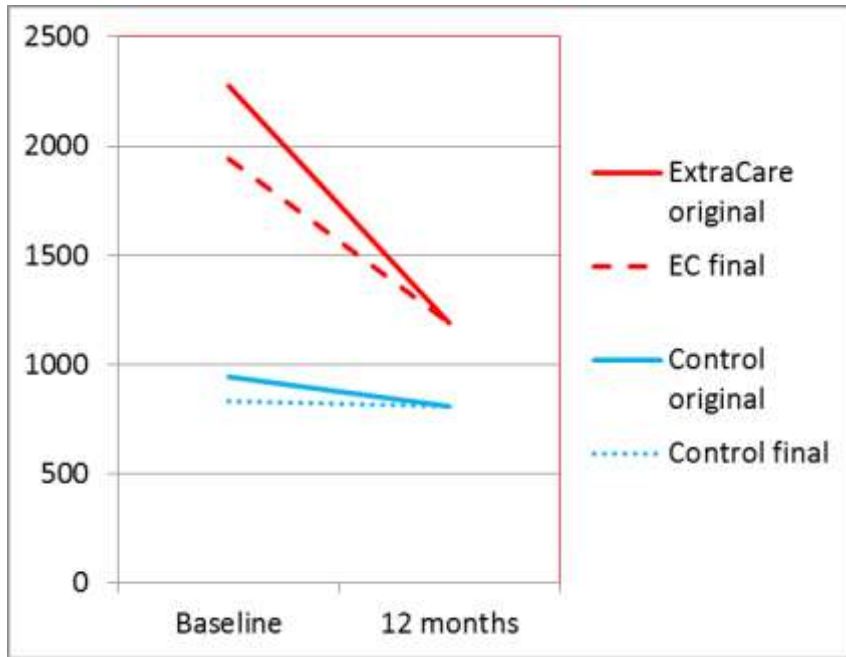
Figure 3: Total NHS costs, comparing baseline with end values (original line) with values for those individuals in the final sample only.

Mean values are used for admissions, not by HRGs (health resource groupings that give costings for specific admissions/procedures).
Total NHS costs were estimated for each participant for the previous year using published NHS tariffs.

6.4 Health profile

6.4.1 Medications and illnesses

ExtraCare participants took more prescribed medications than did controls and had a significantly greater number of chronic illnesses at baseline. However, this was related to the age difference in the samples, rather than any other difference between the groups. However, there were subtle differences in the prevalence of specific co-morbidities. The Control group had more diabetes and Chronic Obstructive Pulmonary Disease (COPD) while the prevalence of cancer and asthma was slightly higher amongst ExtraCare residents. Interesting differences were observed between the two groups with respect to metabolic parameters. The control group fared better in terms of lifestyle factors with a greater proportion undertaking at least 30mins exercise 3 times a week both at baseline and at final follow up. Similarly, the proportion of people eating 4 or more portions of fruit and vegetables was also greater amongst the control group. Over the 18 month period, both groups showed improvements in blood pressure. The change in systolic blood pressure was greater in the ExtraCare group but was not statistically significant. On the other hand there were significant reductions in BMI and Waist circumference between baseline and 18 months in ExtraCare residents while these remained unchanged in control group.

There was a significant initial increase in number of prescribed medications for the ExtraCare group perhaps as well-being support resulted in new diagnoses, but this then remained stable. A reduction in polypharmacy was anticipated, given the use of medication review, but this did not clearly occur.
There was no significant change in number of co-morbidities.

6.4.2 Falls

The "number of falls in the last 12 months" was queried at Baseline and at 12 months. There was a significant overall reduction in falls over the period, with a reduction from an average of 0.66 falls per person at baseline, to 0.36 per person at 12 months. That is, on average, 2 out of three people would have been expected to have had a fall over the last 12 months at Baseline, but this was only just a little more than 1 out of 3 by 12 months later. However, although the control group started off at a lower level (mean of 0.13 falls, a little more than 1 in 10 likelihood), by 12 months their falls frequency had significantly increased to 0.58, or almost 6 in 10 likelihood. This interaction effect was statistically significant (t=2.10, p<0.05) and is illustrated below in Figure 4.
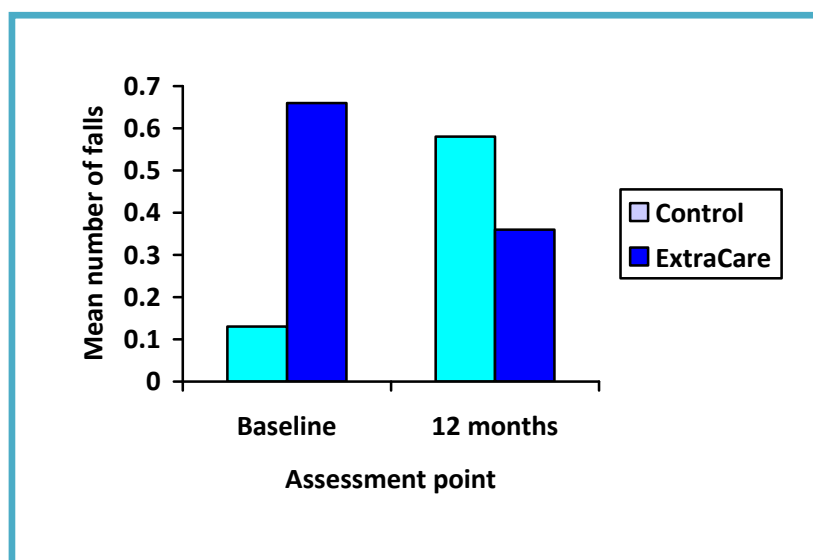

Figure 4: Illustrating the change in mean number of falls over 12 months.

A second piece of data we can examine in this context is number of admissions to hospital as a result of falls. While too small to examine statistically, these numbers mirror those above. For the ExtraCare participants, while there were 8 such admissions reported in the previous 12 months at Baseline, there were only 2 such at 12 months.

6.4.3 Healthcare use

There were no significant differences in numbers of GP visits overall and Hospital admissions in the last 12 months between the groups at baseline, but at baseline ExtraCare participants used their GP more than controls for planned GP visits (routine); this supports the notion that these individuals are initially in poorer health than controls.

However, after 12 months GP (planned) usage by ExtraCare participants had decreased to 1.66 appointments per person per year – a reduction of 46%. No such reduction was seen in the emergency appointment data. We investigated the hypothesis that this may be because residents use the WB drop-in clinic as a substitute for booking routine GP appointments, given that well-being drop-in appointments steadily increased over the period. At baseline, the number of drop-ins and the number of planned GP visits was significantly positively correlated – the more a person visited their GP, the **more** they visited the drop-in clinic too.

However, at 12 months, this relationship had gone completely, and comparison showed a hugely significant interaction between time and visit type, with drop-ins increasing and GP visits reducing over time. Despite this, the relationship for individuals does not become negative which would have been definitive evidence that drop-ins are directly replacing GP visits. That is, it is not the

case that the more a person visited the drop-in centre, the less they visited their GP. This is because this change is not necessarily reflecting individual level changes, just in the group as a whole.

6.4.4 Planned and unplanned hospital admissions and length of stay.

The average number of planned admissions to hospital reduced for the ExtraCare participants over time from an average of 0.19 per person to 0.06 per person (Table 5). There was no change for control participants. For the people who were in the sample at both time points, mean planned admissions per year had fallen by 12 months for both groups. While this is a 31% drop for ExtraCare, the large variance and small effect size means that this was NOT a statistically reliable change. This is illustrated in Table 8.

Table 8: Mean Number of planned admissions per person in the past 12 months

Group	Baseline	12 months
Control	**0.08**	**0.04**
ExtraCare	0.19	0.06
Overall mean	0.17	0.06

Number of unplanned admissions did not change for either group (Table 9).

Table 9: Mean Number of unplanned admissions per person in the past 12 months

Group	Baseline	12 months
Control	0.12	0.16
ExtraCare	0.25	0.24
Overall mean	0.22	022

The median duration of planned hospital admissions did not change over the course of the study (it remained at 1-2 days) but the duration of unplanned hospital stays was recorded as a median of 5-7 days at baseline, but a median of 1-2 days thereafter, showing a significant reduction. Figure 4 illustrates the reduction in length of stay for unplanned versus planned admissions. Planned admissions tended to be predominantly for short investigations or standard procedures such as cataract removal.

We tested the hypothesis that duration of unplanned hospital stays may be less because of the drop-in clinic use, with well-being staff suggesting that admissions may occur earlier in a disease process as a result of earlier advice (before it gets to crisis levels). However, the relationships between the two figures did not support this (no significant correlations).

Note: these figures are based on categories as available in the well-being data, and so percentage reduction cannot be calculated. Recording actual numbers of days in the new database is recommended.
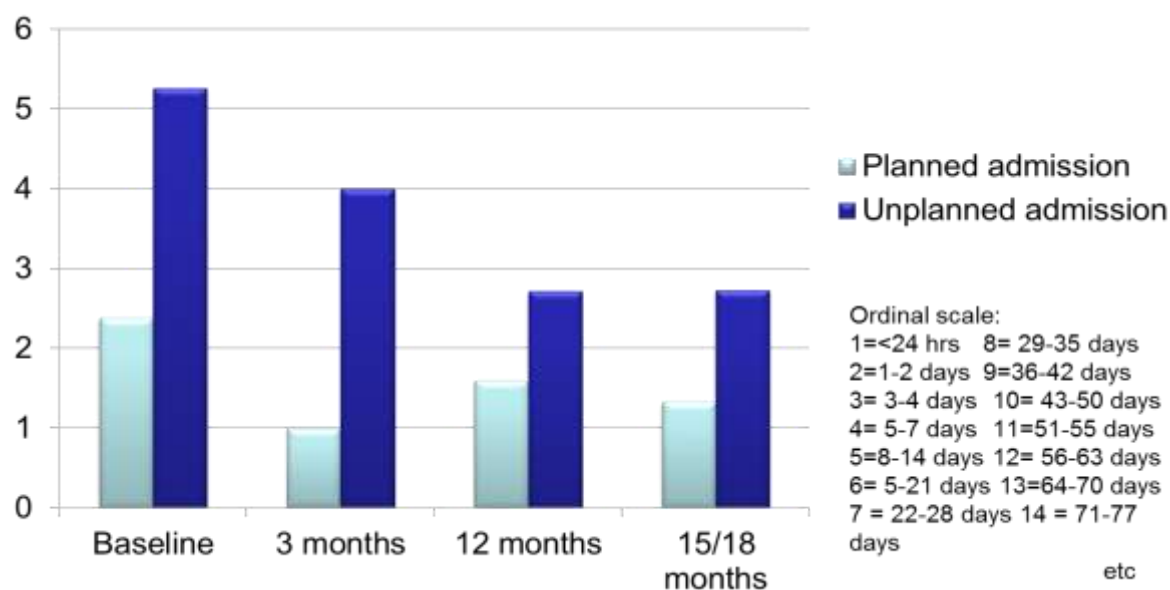
Figure 5: Average length of unplanned hospital stays reduces over time

6.6 Learning Point

> **For ExtraCare:** Careful design of the new database to ensure numbers of days is recorded, e.g. in terms of hospital stays, or number of hours, e.g. in terms of care received, will enable easier reporting in terms of percentage change in the future.
>
> **For policy makers and commissioners:** (i) Availability of local, accessible, relatively informal health support, particularly for ongoing day-to-day chronic illness care, that does not need an appointment (a drop-in service), can have a significant effect on reducing GP usage, giving potential cost savings.
>
> (ii) There was no evidence that such drop in use may also have an impact on length of stay in hospital, although the hypothesis was that admissions may occur earlier in a disease process as a result of earlier advice (before it gets to crisis levels).
>
> (iii) Communities where homes are accessible, care support is readily available and existing care needs understood may result in reduced length of stays in hospital.

7.0 Frailty

Frailty is defined as a state of high vulnerability for adverse health outcomes when exposed to a stressor - that is, an absence of resilience. It identifies an overlapping population at high risk of poor prognosis and high care needs. Depending on the definition selected, estimates of frailty vary from 4% to 17% of the over 65s. **Crucially, frailty, and especially pre-frail states, are <u>malleable.</u>**

7.1 The Frailty Profile

We constructed a frailty summary measure for this population at each assessment to compare longitudinally. We used a Rockwood style frailty profile (Rockwood et al, 2006) based on the total number of indicators we had available from Rockwood's original suggested 70. We constructed this frailty profile based on a restricted set of 30 variables defined for the National ELSA data, plus 19 further items we had available from the original 70.

Rockwood suggests a minimum of one third of these variables be used for any individual, depending on what is available for each person. These included medical indices (e.g. number of chronic illnesses, polypharmacy, BMI), physical robustness (grip strength, walking speed, sit-to-stand ability, BMI extremes, basic independence measures), mental well-being (depression, anxiety) and cognitive health (memory, fluency, instrumental independence measures) amongst others, to define a continuous measure of frailty for our participants.

People were then categorised into **frail, pre-frail** and **not frail** based on Rockwood's criteria.

Of the 44 residents categorised as frail at baseline, 22 remained in the sample 18 months later, 14 (63.6%) remained categorised as frail with 8 returning to a pre-frail or non-frail state, see Table 10.

Table10: Numbers of residents categorised as frail at Baseline; did they stay frail?

	3 months	12 months	15/18 months	
Still in the sample	37	28	22	
Died				8
Frail	22	20	14	
Pre-frail	14	6	7	
Not frail	1	2	1	

Given that the "pre-frail" state is used to indicate people at risk of becoming frail, it is important to know if this occurred for ExtraCare residents. Of the 62 people designated as pre-frail at Baseline, 42 were still in the sample at 18 months and 8 (19%) had returned to a not frail state, with 4.7% being designated at frail at 12 months (see Table 11).

Table 11: Numbers of residents categorised as pre-frail: Did they become frail?

	3 months	12 months	15/18 months	
Still in the sample	57	47	42	
Died				1
Frail	5	12	2	
Pre-frail	40	30	32	
Not frail	12	5	8	

Ten control participants were categorised as pre-frail at Baseline. Of the 8 remaining at 18 months, all were still in the same category. Only one control participant was categorised as frail at baseline and they had returned to a non-frail state by 18 months.

Analysis showed that overall the ExtraCare residents were frailer than the control group throughout, but that both groups improved significantly over the first 3 months. However, the control group showed a significant overall decline over the four assessments (increase in frailty) but the residents did not, although they did return to their initial level after the 3 month improvement. This suggests that initial benefits of moving into ExtraCare are not maintained to the same level (this is mirrored in other variables such as activities too), but also implies that these initial benefits mean that decline over time is not as great as it might be otherwise.

7.2 Putting it together: Frailty and Costs

Total NHS costs for the groups as defined at baseline were examined and overall, as indicated in Section 5, costs in total reduced significantly for each group. Analysing by frail grouping, the reduction for the frail residents was the most dramatic: for those in the sample at baseline and follow-up, this changed from an average of £3274.21to £1588.04 average per person. That is, a 51.5% drop. Use of this figure needs to bear in mind that the most frail amongst this group are those who have died or dropped out of the study. This could not be compared with the control group as there was only one frail member.

Total social care costs were examined in the same way. Although there were still reductions, these were not significant (of the order of £2-300 per person on average). There was, of course, a highly significant increase in care costs associated with increasing frailty status. A frail participant's average annual care costs were £4720.96 at the 12 month point, as compared to £61.40 for a pre-frail resident (given that most pre-frail residents are on zero care). **This underlines the importance of strategies to intervene in pre-frailty to reduce the likelihood of it becoming frail.**

7.3 Learning point

(i)   Initial improvements in frailty did not continue over the full period, although the initial improvements may have delayed decline. Nevertheless, a focus on interventions to prevent or reduce frailty could be further developed and evaluated using such indicators

(ii) Although the majority of people categorised as frail stayed frail, 36% of them returned to a pre-frail or non-frail category.

(iii) Given the very high costs of care for frail older adults illustrated here, but low costs even for pre-frail people, the need to prevent and treat frailty is underlined.

7.4 Physical versus cognitive frailty

In order to determine the source of impacts more precisely, we produced a separate cognitive and physical frailty profile, based on the concept that if someone is physically frail but cognitively unimpaired, they are likely to cope better with the challenges of their illnesses and physical difficulties and therefore may need less care, but cognitive impairment in addition to physical frailty may produce higher care needs. This is illustrated in Figure 5. These numbers should be viewed with caution because there are fewer people in the higher care levels in the data (only 1 person at Care Level 5).
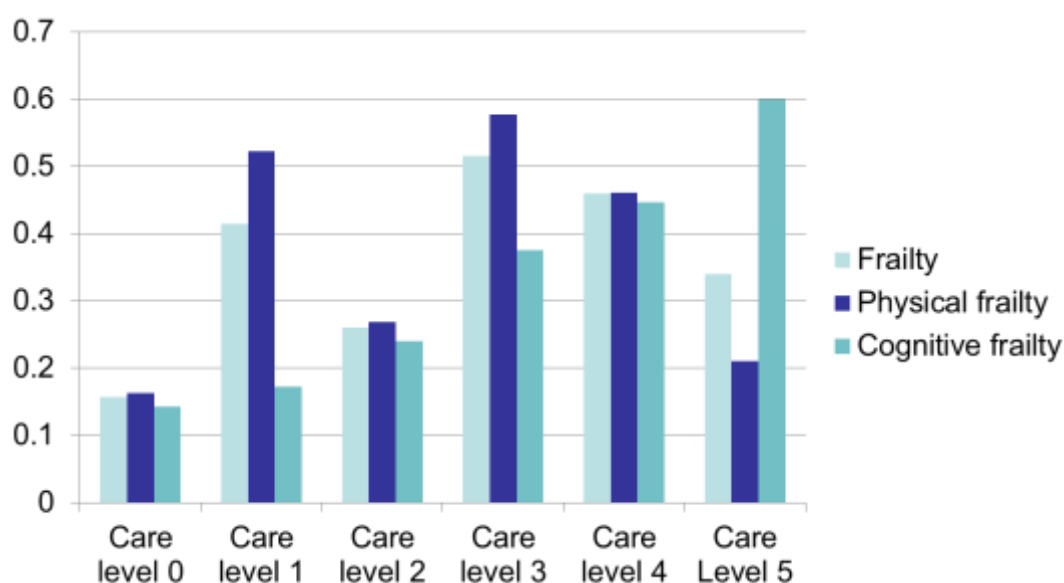
Figure 6: Frailty profile for the different care levels at Baseline

It can be seen that at baseline there is a steady increase of cognitive frailty with increasing care level, but there are uneven jumps in physical frailty from no care (Level 0) to Level 1, and from Level 2 to Level 3.

Data at 12 months was broadly similar (see Figure 6), although at that point there was no one in the sample at Level 5 care. The main difference between Level 3 and Level 4 care was cognitive frailty. The important issue for the model used (the ExtraCare Charitable Trust approach) is that this demonstrates clearly that significant cognitive impairment is being catered for, countering

concerns that people with such impairments may not appropriately be able to stay in independent supported living accommodation.
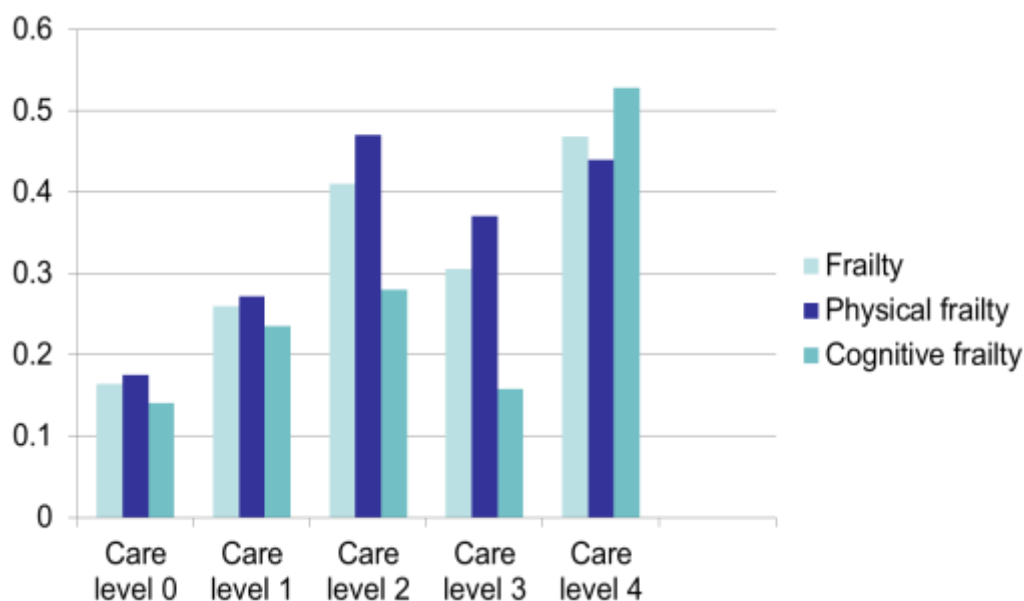
Figure 7: Frailty across the care levels at 12 months (n=90)

8.0 Modelling: What predicts change?

The initial growth curve modelling has demonstrated changes over time for the residents (see Section 4). This section examines whether we can predict some of the changes seen using further modelling.

8.1 Which measures are particularly useful for predicting independence outcomes?

We used a logistic regression model to determine the extent to which we could predict a decline in the measure of independence used (decline vs. no decline), Instrumental activities of Daily Living, IADLs.

The model assessed the contributions of: baseline frailty, physical frailty and cognitive frailty, then of change in variables: perceived health, depression, overall cognitive functions (using the ACE-R), change in autobiographical memory function, change in walking speed, change in overall frailty, change in numbers of chronic illnesses, and of course, which group people belonged to (residents vs control group). The model was significant, predicting 25% of the variance in whether or not someone declined in their IADL. It correctly classified 96% of those who did not decline, but only 23% of those who did decline, which is rather low, suggesting that there are more factors having an impact on decline in IADL than we have included (this was 30% when Residents were considered alone, a little better). Nevertheless, the specific variables of **change in ACE-R** and **change in frailty** had a significant impact on the **outcome decline in IADL**. For example, for every

one point increase in ACE-R, it became less likely that IADL would decline. This did not differ by group.

We then examined the same model for predicting declines in our more extensive functional limitations profile. Given the greater variance in this measure, we used a decline of more than 1 standard deviation to indicate significant decline. Again, group did not make an overall difference to how well we could predict whether functional limitations would increase. For the residents, the model was significant, predicting 44% of the variance, correctly classifying 91% of those who showed no decline and 44% of those who declined. The most salient contributors were **baseline age** and **increase in depression**: e.g. for every one year increase in age within the sample, people were 1.13 times more likely to show an increase in functional limitations and for every one point increase in depressive symptoms, people were 1.36 times more likely to decline (increase) in functional limitations.

In summary, change in cognitive function and in frailty had a specific impact on the likelihood of people's IADL declining over the period, and change in depression level and baseline age both predicted the likelihood of declining in functional limitations.

8.2 Learning point

> A focus on rehabilitation and improvement of cognitive function and on treatment or prevention of depression will have important direct effects on independent function and quality of life, and therefore need for further care and support.

8.3 Which measures are particularly useful for predicting Care level?

Given that there are significant relationships with a large number of our variables and Care level, we conducted an analysis to determine which were the strongest predictors of care level overall. The most salient predictors were **overall frailty, IADL and ADL** (a more basic independence measure), and **ability to stand up from a chair** (time taken or inability). 36% of the variance is predicted by these variables alone, underlining the importance of these screening measures.

However, unexpectedly, we found that **good linguistic ability** was also an important predictor of Care Level. Individual relationships showed that, as with other cognitive skills, better performance predicted lower care level. But once frailty, IADL and ADL, and sit-to-stand was taken into account, **language had an opposite effect** – people with higher language ability were **more** likely to have higher care levels, suggesting that those who could communicate well and understand information may be more likely to get the care they need. This has important implications for an advocacy role for frail people in helping them get the care they need. To examine this further, a comparison between those categorised as frail who receive care against those who do not confirmed this – those receiving care and therefore hopefully being enabled to a better quality of life in the context of illness or physical impairments, had better language skills, with this being most salient at lower levels of care (1 to 3) and at Baseline. That is, this issue reduces, but does still have an overall effect across the full period.

8.4 Learning Point

(i)   Care level is strongly predicted by assessments such as IADL and ADL, which of course form part of an assessment for what care is needed. However, as shown in Learning Point 7.2, these measures are variable and can be impacted by change in the underlying predictors of IADL and ADL, which would then have an impact on care needed.

(ii) Communication and linguistic skills are needed for a person to be able to get the care they need and understand information available. Poorer linguistic abilities seem to result in people being less likely to get care, even in the context of frailty.

(iii) Support in ExtraCare seems to reduce this effect over time (the effect is less at later time points), but the fact that there is still an effect highlights a need for more advocacy.

8.5 Which measures are particularly useful for predicting well-being outcomes?
Findings have shown reliable improvement in depression, autobiographical memory specificity and in perceived health over the periods that is specific to the ExtraCare sample, variables that can together be classed as well-being.

The main predictor of this in the total sample is group, wherein living in ExtraCare predicts these improvements. But can we tell any more from within the ExtraCare data as to what predicts such change?
In a model to predict whether a resident's depression score improved from Baseline to the final assessment, frailty was included at both points as were change in frailty, change in autobiographical memory performance and perceived health, change in anxiety, change in IADL, change in functional limitations and change in cognitive function (ACE-R). Number of chronic illness diagnoses at 12 months was added. The model predicted 33% of the variance (Chi-squared = 20.43, $p < 0.05$), and correctly classified 94% of those who showed improvement in depression and 40% of those who did not. The significant predictors within the whole model were **change in cognitive function**, such that an improvement of one point on the ACE-R increased the chance of depression improving by 1.12 times, and **change in anxiety**, such that an increase in anxiety of one point reduced the chance of mood improving by 0.78 times (people were approximately only ¾ as likely to improve on their mood if their anxiety increased). Number of chronic illnesses was marginally significant ($p < 0.1$) again reducing the chance of improvement in mood as numbers of illnesses increased and should also be borne in mind.

Having demonstrated an important role of cognitive improvement in prediction of depression improvement, we then investigated what aspects of cognitive function were the important components here. For example, data has shown an overall improvement in Memory: is that having an effect here?

The model using the detailed breakdown of cognitive variables demonstrated that the cognitive variables alone accounted for 22% of the variance in whether or not someone would improve in

their mood (p<0.01), correctly classifying 92% of improvement cases. **Fluency, our indicator of executive function** (ability to allocate and control attention appropriately) was the only significant predictor within this, demonstrating that a one point increase in fluency increased the likelihood of improving in mood by 1.45 times.

8.6 Learning point

> Any interventions known to improve executive function specifically will be expected to reduce depression incidence and improve mood. There is very robust evidence in the scientific literature for an increase in physical activity having this effect amongst older adults, including those with significant cognitive impairments and dementia.

8.7 Which measures are particularly useful for predicting frailty outcomes?

As indicated in Section 6, while a frail status was highly predictive of care level and total care costs, it was something that did, for some people, change. Given the very striking difference in health and social care costs for frail versus pre-frail people, it is important to attempt to work out predictors of reducing frailty over the period.

Similar modelling was conducted. Baseline frailty, age, depression measure, overall cognitive function, autobiographical memory, whether or not a person received formal care and group (Resident or control) were entered. Only measures not already included in the construction of the frailty profile could be used. The model predicted a significant 33% of the variance in whether or not someone's frailty increased or not (they became more frail). 73% of those who did become more frail were correctly classified by this model. Within the model, the salient predictors were **change in autobiographical memory and change in ACE-R,** an increase in each reducing the likelihood of frailty increase. Baseline frailty had the same effect, in that **initial frailty** predicted lack of decline (people were only one third as likely to get worse if they were already frail).

This result implies again that maintaining and improving cognitive and socio-emotional measures of cognition where possible will have a positive impact on frailty change, underlining the importance of interventions known to improve these factors. This is in addition to the importance of changes in the underlying measures that make up the frailty profile, notably physical weakness, which can improve as a result of carefully designed exercise programmes.

8.8 Which measures are particularly useful for predicting NHS cost outcomes?

Using a linear regression procedure to determine the predictors of variance in amount of change in NHS costs from Baseline to 12 months, we examined a model that included: age, group, change in cognitive measures, change in anxiety, in perceived health, in IADL and functional limitations, change in number of visits to the drop-in clinic and change in number of falls. Age and group had no impact and so the model was examined for ExtraCare residents only. The total model was highly significant (p<0.001) predicting a total of 56% of the variance in NHS cost change. Within the model, the only predictor that made a significant impact individually was change in **Instrumental activities of daily living** (IADL), t=-4.23, p<0.001. The unstandardized coefficients indicate that **for every 1 point increase in IADL, there is a £2221 reduction in NHS costs** if all other variables are held constant (nothing else changes).

8.9 Learning Point

Taken together, in terms of reducing NHS costs, it seems that an important focus is to improve Instrumental Activities of Daily Living, which our earlier analyses suggest are significantly impacted by change in depression and cognitive function.

However, further analyses will be able to determine whether lifestyle changes such as physical activity, or further preventive activity has any further impact.

9.0 Benefits of further screening

The above analyses have all indicated benefits for some of the screening measures that we added to the total screening that ExtraCare does. The recommendation is that the Well-being Advisors consider the following variables as to whether they would be useful for identifying people who might be missing out on care they need or on other interventions that may reduce decline. The opposite is also the case – there may be people receiving support for issues they no longer have concerns with (e.g. depression that has been alleviated).

9.1 Frailty

The frailty profile we produced predicted 48% of the variance in care level (p<0.001). However, our data indicated a significant number of people categorised as frail who were not receiving care support, see Table 12. The low percentage of people designated as frail who were receiving care at 12 months underlines the need for regular screening of needs.

NB: At all levels it is expected that there are people who are frail but who receive informal care from family members or privately arranged means who will be part of these figures as frail people not receiving care.

Table 12: Numbers (percentage) of people designated as frail who were not in receipt of formal care.

Baseline	3 months	12 months	15/18 months
12 (35%)	8 (36%)	17 (61%)	3(33%)

9.2 Depression

The well-being screening identifies people with a diagnosis of depression only, it does not perform any standardised screening. We used the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) which is widely used and is filled in by the participant, and so no specific training is needed. A level of 8 or more on either anxiety or depression sub-scales indicates possible clinical levels which need to be followed up.

There was a significant mismatch between those identified by this measure and those identified in the screening measures as depressed, Illustrated in Table 13. This illustrates that ExtraCare identified 15 and 22 people with diagnoses of depression at baseline and 12 months respectively,

and the screening measure identified 16 and 15 people respectively. The groups however did not tie up, with 11 and 7 people identified at the respective time periods who had significant levels of depression but no diagnosis on the well-being data. The percentage of unidentified people with probable depression reduced over the period from 68.8% to 46.7%, but further screening to support these efforts further is recommended. During the period covered by the study, people referred to the "Locksmiths" (support for people with cognitive impairment and mental health concerns) began to be screened using the Geriatric Depression Scale. This may be the source of the very positive reduction of unidentified people with probable depression, but the point at which screening is conducted could be usefully further considered, with the numbers still being missed suggesting a benefit for population based screening, as opposed to only screening those referred. Number identified in the following table includes those for whom "referred" was indicated in the well-being data.

Table 13: Identification of people with clinical levels of depression:

Number Identified at Baseline (BL)	Number identified at 12 months	Number not identified at BL	Number not identified at 12 months	Total with scores indicating depression at BL	Total with scores indicating depression at 12 months
15	22	11 (68.8%)	7 (46.7%)	16 (10.8%)	15 (11.8)

9.3 Cognitive function

We used the overall ACE-R cut-off scores to indicate people with mild cognitive impairment and levels of performance indicative of possible dementia. We then compared those against numbers working with the Locksmith, indicated in brackets in Table 11.

Table 14: numbers of residents identified in categories for possible dementia, Mild Cognitive Impairment (MCI) and no concern, as compared with Well-being recorded diagnoses.

Level	BL ACE-R	Total BL well-being: Diagnosis/shows symptoms	12 months ACE-R	Total 12 month well-being: Diagnosis/shows symptoms
No Concern	88		63	
Probable MCI	43		25	
Probable Dementia	29 (3)	5 (3)	17 (1)	7 (1)

Baseline:

Of the 29 people with scores indicative of dementia, only 2 had a diagnosis on their well-being chart. Only 3 of the 29 were working with the locksmith, but 6 other people without such a diagnosis or scores indicative of dementia were doing so. Three of these were people our

screening identified as having scores indicative of mild cognitive impairment (MCI), out of a possible 36 people in this category.

12 months:
Of the 17 with scores indicative of dementia, only 5 had a diagnosis of dementia and only 1 was working with the Locksmith, but again 6 others (scores outside of the range indicative of dementia and no diagnosis on well-being chart) were doing so. One of these was a person our screening identified as having scores indicative of mild cognitive impairment (MCI), out of a possible 24 people in this category.

NB ExtraCare have indicated that Locksmith data and well-being data may not quite match up, so there may be more people receiving this support than the well-being data suggests.

9.4 Learning Point

(i)   there are a lot of people who may benefit from specific support for cognitive impairment or for depression who are not receiving it.

(ii)   Screening for frailty, depression and cognitive impairment is recommended.

(iii)   However, these data also confirm that people with other perceived difficulties than clear cognitive impairment are benefitting from the locksmith programme.

10.0 In depth analyses on specific issues

Throughout the analyses we have examined variables that benefit from living in ExtraCare and how those specific variables are predictive of other changes. There now follow summaries of specific in depth analyses which further support decision making in terms of future development of services for ExtraCare, lifestyle changes or rehabilitation strategies residents can take up, or further developments for us as researchers. There are further examples in the Factsheets.

10.1 Autobiographical memory.

Given our findings and the background literature, Autobiographical memory specificity was investigated as an intermediary functional measure of memory lying between basic cognitive function in older age and social functioning and independence outcomes. It was also investigated as an intermediary functional measure of memory lying between underlying mood or depression in older age and functional outcomes.

Analysis indicates that while autobiographical memory test performance (AMT) acts as a clear mediator between general cognition and outcome independence (as assessed using IADL) at baseline, after 3 months and subsequently, this is not the case, see Table 12 below. However, it can be seen that AMT consistently mediates between underlying cognition as assessed in terms of the specific fluency measure, and outcome perceived health, as a measure of well-being.

Furthermore, it can be seen in Table 12 that AMT consistently mediates the effects of depression on outcome IADL, perceived health, and recreational functional limitations (ability to do ones hobbies and pastimes).

Table 15. Autobiographical specificity as a mediator?

Relationship: AMT as a mediator between:	Baseline	3 months	12 months	18 months
ACE-R and perceived health	✗	✗	✗	✗
MMSE and perceived health	✓	✗	✗	✗
ACE-R and IADL	✗	✗	✗	✗
MMSE and IADL	✓	✗	✗	✗
Depression and Perceived health	✓	✓	✓	✓
Depression and IADL	✓	✓	✓	✓
Depression and Recreation function limitations	✓	✗	✓	✓
Fluency and perceived health	✓	✓	✓	✓
Fluency and IADL	✓	✗	✗	✗
Fluency and social function limitations	✗	✗	✗	✗
Fluency and Communication Limitations	✗	✗	✗	✗
Fluency and total limitations	✗	✓	✗	✗

We know from this analysis and also from the background literature that AMT is affected by depression and vice versa. For example, it has been shown that improving AMT by training can have a significant positive effect on mood in people with depression, reducing the likelihood that they will have a relapse once recovered.

We therefore asked the question of whether AMT and depression also act together as mediators to enable us to predict outcomes like IADL, perceived health or functional limitations. That is, given that we already know that AMT affects depression, and we have just shown mediation of the effect of depression on functional outcomes, how do they work together?

We examined this model and find that when the predictor is Fluency, and outcome is total functional limitations, there is a significant total mediation effect, and a forward effect of AMT on the effect of depression. Depression has a negative mediation effect on functional limitations whereas autobiographical memory (AMT) has a positive effect. This means that **good autobiographical memory is diminishing the effect of depression on IADLs.**

That is, both depression and AMT are working together to mediate the impact of fluency on functional limitations. Within this, AMT determines how much depression has an influence. **If AMT is higher, then depression will have less of an influence and vice versa.**

That is, even in the context of changes in cognition and depression, if autobiographical memories can be recalled in a specific detailed manner, outcome functional limitations will be less affected. This effect was robust throughout the different assessments.

10.2 Learning Point

This has important implications for:
(i) ExtraCare – should Locksmiths be including specific autobiographical training or rehabilitation in their support?
(ii) Residents – practicing recalling specifically rather than in an over-general manner can have important benefits.
(iii) Us as researchers: we have now started a new piece of research (with a new PhD student) to investigate what are the best ways of improving autobiographical specificity and what works best for unimpaired and for cognitively impaired participants.

10.3 Mild Cognitive Impairment

Mild cognitive impairment (MCI) is defined as cognitive decline greater than that expected for an individual's age or education level but outside of the context of dementia. Reported prevalence varies, with annual incidence rate ranging from 55 to 77 per 1,000 persons aged 60 or over. MCI is considered to be a symptomatic pre-dementia phase of Alzheimer's Disease (AD), with estimates ranging from 15-41% of MCI cases per year going on to develop AD or dementias. One four year study found a mean annual conversion rate of 11% when assessed using the Addenbrooke's Cognitive Examination (ACE-R) criteria (Lonie, et al., 2010).

Conversely, studies have also shown that up to 44% of patients with MCI return to a non-MCI diagnosis a year later (Ritchie, 2004; Ganguli, Dodge, Shen, & DeKosky, 2004). Thus MCI could be viewed as a transient and high risk phase, and interventions to promote improved health or cognitive functioning could be particularly pertinent for this group.

People in the sample within the range for probable MCI were identified as defined on the ACE_R scale (score of 76-86 out of 100).

Decline was defined as ACE-R reducing by 1 Standard deviation (SD) or more using the SD from the unimpaired group, given that the impaired group was more variable. This meant a reduction of 5 or more ACE-R points was used as indicative of significant decline outside of normal variation. Of the 24 MCI participants remaining in the study after 12 months, 19 (79.2%) stayed the same or improved, and 5 (20.8%) declined, with 5 (20.8%) within range for dementia. 3 (12.5%) had reverted to normal cognitive functioning. These are small numbers of people compared with the larger previous studies cited, and so should not be directly compared, but what is important is that the ExtraCare residents with MCI were no more likely to decline over the period than the initially unimpaired participants: 92.53 % either stayed the same or improved and 7.5% declined. That is, although it appears that the MCI group were more likely to decline over the period, this difference was not significant at p < 0.05. (χ^2 =3.23, p=.07).

There were some initially promising differences for the MCI group in that they showed initially greater improvement in visuospatial skills and in AMT than the unimpaired group (baseline to 3 months); however, their performance then declined again but did not return to its initial level for AMT but did for visuospatial skills. These small indicators suggest that the impact of these early benefits of living in ExtraCare may be delaying the decline that would put people into the possible dementia category, but also further demonstrate that initial transitions are not maintained, suggesting that more could be done to improve ongoing support after the first 3 months.

We examined the predictors of cognitive decline using similar modelling procedures to earlier sections (Logistic regression), comparing decline between BL and 15/18 month assessments. Baseline age, depression, ACE-R scores, and number of the specific chronic illnesses were controlled for, and changes in depression, anxiety, perceived health and IADL (from baseline to 15/18 months) were entered into the model.

The model was significant ($p<0.05$), predicting 32% of the variance. The model only classified 18% of decline cases but 95% of no decline cases. The key variable that was a significant contributor to the model was **change in depression score**. For every 1 point increase in depression score, people were 1.64 times more likely to show significant cognitive decline over the period (95% CI 1.15 to 2.33). **Note that this analysis excludes people in the dementia range at Baseline.**

10.4 Learning Point

This has important implications for:
(i) ExtraCare: being aware of depression and encouraging residents to seek help for it may reduce the likelihood of cognitive impairment as well as reducing depression.
(ii) Residents: Understanding that stress and low mood can have an impact on cognition may encourage people to seek help for psychological issues they may otherwise be unwilling to admit.
(iii) Us as researchers: examining the opposite effects, the effects of alleviation of depression on longer term outcomes is the next step.

11.0 Dissemination activities

Throughout the three years we have given presentations of various aspects of the research at conferences in the UK and internationally. We have included some of these presentations in the portfolio.

A book chapter, a Response to the Commission on the Future of Health and Social Care in England, and an EU Active and Healthy Ageing Good Practice were all submitted and accepted for publication. Further articles have been submitted to high profile academic journals.

We have also completed quarterly reports aimed at residents, which are disseminated via the website and to well-being staff to share hard copies with residents. http://www.aston.ac.uk/lhs/research/centres-facilities/archa/extracare-project/quarterly-reports/

12.0 Other outcomes

12.1 Costing Tool

Attached to this report is a summary and instruction manual for the costing tool designed as part of this project. This tool, works out approximate social care and health costs for individuals, based on a database and built in **Microsoft Access**. Based on data from their Well-Being assessment – including number of GP appointments and level of care received, the tool uses published rates for social care (at ExtraCare village/scheme and local authority level as appropriate) and health tariffs

(at national level) and gives an estimate of how much each person's care has cost during the previous 12 month period. Costs are calculated at ExtraCare rates and also local authority rates. Differences can then be computed to determine if health and social care costs are more/less/equal for those living in ExtraCare compared to their own homes in the community. The costing tool will need updating annually with the most recent care costs.

12.2 Frailty screening

Attached to this report is also a description of the creation of the frailty profile. Evidence suggests that screening for frailty based on data already collected would be useful in terms of identifying people who could be offered a little more support.

13.0 Recommendations and actions from the management team at ExtraCare

ExtraCare plan to take the learning points from this research and put them into action to further enhance the lives of residents. A small learning group will be established to take the points forward and translate them into reality. The following actions are being planned or have already been implemented:

- The introduction of the Frailty Calculator as part of the Well-being Assessment to monitor frailty levels and ensure correct interventions are triggered such as referral to the Otago exercise group (http://www.extracare.org.uk/care-services/our-well-being-service/otago)

- Transition to ExtraCare - establishing peer mentor support, buddying system to facilitate new residents induction to ExtraCare and to enable friendships and networks to be established. This will be the theme for the annual Well-being Conference in 2015

- The introduction of Housing Assistant support posts to ensure that an annual review takes place of residents' activities of daily living (as well as annual well-being assessments) and to refer if there appears to be a need for care

- raising awareness with the staff team who carry out care reviews of the issue of language capabilities as a barrier to accessing care – so they can advocate on behalf of residents to the Local Authority in respect of a care need or change in care need

- Identification of those residents with depression – we have introduced the GDS tool to identify those residents with depression and have already implemented training on stress and anxiety

- We need to use the outcomes from this research and introduce a user friendly information guide which illustrates the importance of physical and intellectual activities, and use the Well-being Champions (residents) to disseminate this information to ExtraCare communities

- To investigate the re-introduction of small street meetings in each location to facilitate neighbourhood friendships

- Recruiting a Pharmacist on the staff team at head office which will help us review the polypharmacy themes

Changes in the health and social care landscape over the period of this research may have impacted on the care service provision. It is important that we continue to communicate these

changes to the residents so that they may understand them. There has also been a re-assessment and alignment of residents care needs to match care plans and staffing levels over this time frame due to an over delivery of these services which were unfunded. We need to ensure this message continues to be communicated well to residents.

We will continue to look for funding opportunities to expand the Locksmith service which is currently being financially supported from the charities shops income. We will look for funding to continue the quantitative element of this research to provide a longer view of the health and social care outcomes identified in this report.

14.0 References

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