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Doctoral Thesis: Caregivers' engagement with online support.

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Word Count

Section	Text	Figures and Tables; References; and Appendices	Total
Abstract	293	0	293
Research Paper	7,911	10,927	18,838
Literature Review	6,963	6,202	13,165
Critical Appraisal	3,997	915	4,912
Ethics Section	878	14,665	15,543
Total	20,042	32,709	52,751

Abstract

This thesis is comprised of a research paper, a literature review and a critical appraisal of the research process.

The research paper investigates the use of a digital health intervention (DHI) by relatives of people with psychosis or bipolar disorder, with the aim of identifying the factors which impact their engagement. Individual interviews were conducted with participants, recruited through NHS Early Intervention in Psychosis services in the UK. An inductive thematic analysis resulted in three themes: (i) motivation to understand and be understood; (ii) personal relevance sustains engagement; and (iii) usability and interaction enhance engagement. The findings indicated that clinical support from a trusted source was critical to engagement. Participants also appreciated the opportunity to relate to relatives facing similar challenges in order to access support and learn new strategies. This implied that the development and implementation of DHIs should include input from caregivers to ensure content and delivery reflect the needs of the intended user.

The literature review identified and synthesised the findings of 34 qualitative studies about how caregivers of people with physical or mental health conditions engaged with online peer support. Thematic synthesis resulted in two overarching themes which represent the function of online peer support for the participants: (i) meeting caregivers' needs for a new type of sustaining friendship; and (ii) creating a space to express uncomfortable emotions. Caregivers' engagement with flexible, emotionally supportive and reciprocal interaction online was underpinned by experiential similarity. Online peer support offered a safe space to express emotions away from the caregiving relationship and has potential to meet caregivers' needs for support.

The critical appraisal reflects on the findings of the research paper and the literature review, focussing on limitations; opportunities for future research; and the impact of reflexivity on the research process.

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Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University’s Division of Health Research between September 2017 and September 2020. The work presented here is the author’s own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Johanna Barraclough
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Date: 7th September 2020

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I am extremely grateful to my supervisors for their constant support, encouragement and inspiration.

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Section One: Research Paper

Implementation of a supported self-management digital intervention for relatives of people with psychosis or bipolar disorder – the relatives' perspective.

Prepared for submission to *Patient Education and Counseling*[1]

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[1] Please note this paper was prepared in line with the author guidelines for *Patient Education and Counseling* (See Appendix 1A). The word count is in line with University guidelines rather than journal guidelines.

Implementation of a supported self-management digital intervention for relatives of people with psychosis or bipolar disorder – the relatives' perspective.

Abstract

Objective: This study aimed to enhance understanding of the implementation of a Digital Health Intervention (DHI) in NHS mental health trusts from the perspective of the end users. The study is a component part of a wider multiple case study, "*Implementation of an online relatives' toolkit for relatives of people with psychosis or bipolar experiences: the IMPART multiple case study.*" The DHI is an online toolkit designed to provide support and information to relatives of people with psychosis or bipolar disorder: The Relatives Education and Coping Toolkit ("REACT"). The objective was to identify the factors which impact participants' engagement with REACT.

Method: Twenty-three individual interviews were conducted with relatives of people with psychosis or bipolar disorder, recruited through NHS Early Intervention in Psychosis (EIP) services in the UK. An inductive thematic analysis was applied to transcribed interview data.

Results: Three themes (with subthemes), representing key factors impacting participants' engagement were identified: (i) motivation to understand and be understood; (ii) personal relevance sustains engagement; and (iii) usability and interaction enhance engagement. Positive engagement factors relating to REACT were characterised by human interaction and the perception that the intervention was personally relevant. Engagement was facilitated by interaction with clinical staff, underpinned by an understanding of the needs of caregivers. A motivator to engage with REACT was the opportunity to relate to people facing similar challenges to access emotional support and to learn new strategies.

Conclusion: For DHIs to be effective and engaging, clinical support from a trusted source is important, particularly at the point of introduction. The design of a DHI should recognise the value that end users place on the ability to interact online with peers and its importance to engagement.

Practice implications: Involving service users and caregivers in the development and implementation of DHIs is fundamental to ensuring that content and delivery are beneficial and in line with the lived experience of the end user.

1. Introduction

1.1 The need to support caregivers

Relatives and friends of people with long-term physical or mental health conditions provide extensive care, with the number of caregivers in the UK in 2019 estimated at 8.8m [1]. The significant economic value of caregivers' activity has been recognised [2, 3], with care provided by relatives of people with severe mental health problems estimated as saving the NHS £1.24bn per year in the UK [4].

Whilst caring for a relative can be a positive and fulfilling experience which strengthens relationships [5], it is also associated with high levels of distress and significant emotional, practical and financial burden [6-11]. In addition, distress and burden experienced by caregivers affects their capacity to provide care, as the health outcomes of caregivers and the people they care for are interrelated [12]. Caregiver burden is compounded by living with the person with psychosis; awareness of suicidal ideation [13]; reduced social support [14]; and caregivers' beliefs about the origins of psychosis [15-17]. Caring for someone with bipolar disorder is impacted by the distress associated with a high prevalence of suicide attempts compared with other mental health problems [18]. Extreme behaviour during manic episodes together with the challenges of depressive episodes in bipolar disorder can be distressing for the caregiver and the wider family, leading to anger, anxiety and helplessness [19].

The need to support relatives is reflected in UK government guidelines. The National Institute for Health and Care Excellence (NICE) (2014) [20] guideline for psychosis recommends the provision of an education and support programme for relatives, and NHS England (2015) [21] access and waiting time standards for mental health services require psychosis teams to offer families a caregiver focussed support and information programme. However, historic implementation of this guidance to support relatives is poor. An audit of psychosis services in the NHS in 2019 showed that only 55% of relatives received a caregiver focused education and support programme, and only 22% received structured family intervention [22]. The findings of an audit of a mental health trust in North West England reported much lower numbers, with 1.6% of service users offered family intervention, and only 1.1% receiving it [23]. The picture is similar across Europe, with up to 15% of families reported as receiving interventions [24].

1.2 Context

This study formed part of a National Institute of Health Research (NIHR) funded project, which aimed to identify the key factors behind the successful implementation of an online supported self-management intervention in the NHS: "*Implementation of an online relatives' toolkit for relatives of people with psychosis or bipolar experiences: the IMPART multiple case study.*" The intervention is the Relatives' Education and Coping Toolkit (REACT) and was designed for relatives of people with psychosis or bipolar disorder [25]. REACT was developed in response to a clinical need to provide relatives with information and support, reflected in NICE guidelines [20] and NHS targets [21]. The challenges associated with providing clinical and cost-effective services to manage long-term health conditions has led to the development of supported self-management digital health interventions which are designed to be used in clinical settings with support from healthcare staff.

Digital health interventions (DHIs) can be defined as healthcare delivered via a digital platform [26]. Whilst the development and evaluation of DHIs to support people with physical and mental health conditions and their families has been prolific, there is an evidence-practice gap and a lack of clarity about how to implement these interventions [27, 28]. The IMPART study aimed to address this through an iterative case study design, analysing quantitative and qualitative data from a range of sources about how REACT is introduced and used across six NHS Mental Health Trust sites [25]. The present study focussed on the collection and qualitative analysis of one specific element of these data, the relatives' experience of the implementation of REACT in their NHS Trust. Enhanced understanding of end users' experiences of REACT should lead to transferable knowledge about the factors which impact peoples' decisions to explore and engage with DHIs.

1.3 The Relatives Education and Coping Toolkit (REACT)

REACT is an online toolkit, which provides evidence-based information and support for relatives of people with psychosis or bipolar disorder. REACT was co-produced with service users and relatives and initially produced in a paper booklet format before being developed as a website for the IMPART study. REACT was designed to be introduced to relatives by Early Intervention in Psychosis (EIP) services in UK NHS Mental Health Trusts and represents a way for services to meet government guidelines for supporting relatives. REACT contains 12 modules, which can be accessed as needed. The content includes psychoeducation, videos of clinicians and relatives sharing their experiences, a resource directory and a moderated forum. Relatives are supported in their use of REACT by EIP staff. REACT has been shown as effective in reducing distress and improving perceived support and ability to cope in relatives of people with psychosis in EIP services [29]. A nationwide online randomised controlled trial funded by the NIHR (Health and Technology Assessment) launched in October 2015 with the aim of testing the clinical and cost-effectiveness of REACT [30].

1.4 Implementation of Digital Health Interventions

Digital Health Interventions (DHIs) are rapidly being developed for psychosis and bipolar disorder, with evidence supporting their feasibility and acceptability [31-34]. Whilst there is substantial investment and evidence to support DHIs, their implementation in healthcare services is in its infancy. Barriers have been identified at systemic and individual levels as it can be challenging to embed a DHI in existing clinical services due demands on resources, which in turn can impact service users' enrolment and engagement with the intervention [35, 36]. Barriers to user engagement with DHIs include seeing no value in the intervention; a lack of information technology (IT) skills [37] and negative attitudes about IT [38]; fears about receiving a poorer level of clinical care due to the impersonal nature of the DHI [39]; and a preference for face-to-face care [40]. Enhanced understanding of the factors which support successful transition from evidence to practice is needed to maximise the potential benefits of DHIs and minimise the risks associated with healthcare delivered via online platforms. These risks include breaches of confidentiality for personal and sensitive data and IT system failures [41].

1.5 Engagement with DHIs

This study explored factors affecting engagement with REACT from the perspective of the relatives, including how they became aware of REACT; their decision-making process about using REACT and creating an account; and the extent of its use. The aim was to capture the experience of each stage of this process. A synthesis of qualitative research focussing on initial engagement and enrolment to DHIs highlights that the reviewed papers focused on specific elements of this activity rather than the whole process [42]. This highlights a need for research with broader focus which includes exploration of interaction between implementation activities at the service level together with user uptake and engagement. Whilst this study focussed on user engagement, it is a component of a wider implementation study and recognises the influence of implementation activities on the end user.

This study’s focus on caregivers of people with bipolar or psychosis’ experiences of the implementation of a DHI also addresses an area of limited research. A recent systematic review examined implementation factors impacting DHIs for psychosis or bipolar and found no studies relating to interventions for relatives or caregivers [27]. Implementation factors reported in the review included attitudes and beliefs about DHIs, the complexity, accessibility and adaptability of the intervention, and the availability of clinical resources. However, it is unknown whether these factors are also relevant for caregivers or relatives of people with psychosis or bipolar.

A systematic review investigating usability and acceptability of DHIs for caregivers of people with physical or mental health problems found three papers which focussed on DHIs for caregivers of people with psychosis or bipolar [26]. This research indicates that online interventions have the potential to be useful, supportive and relevant to relatives of people with psychosis or bipolar [43-45]. However, whilst these studies examined how caregivers used the DHIs, their experience of the way they were implemented was not explored. The importance of the introduction to the DHI is suggested by the findings of a systematic review which explored hypothetical acceptability of DHIs to people with serious mental health problems together with actual acceptability [32]. The review found that hypothetical acceptability, referring to participants’ initial perceptions of DHIs was relatively low compared with actual acceptability, which was high when measured after accessing an intervention. Whilst the review focussed on service users rather than caregivers, it suggests an opportunity to investigate how users' preconceptions and fears about DHIs are addressed when a DHI translates from a hypothetical concept into a useable and acceptable tool.

This study aimed to enhance understanding of the process of engaging with a DHI, from the perspective of relatives of people with psychosis or bipolar disorder being introduced to and using REACT, to identify the key factors affecting engagement.

2. Methods

2.1 Rationale and design

The study has a qualitative design to allow participants' views and experiences of being offered REACT to be captured in depth through semi-structured interviews. Thematic analysis was chosen as it facilitates the identification of patterns of meaning in data in response to the research question [46, 47]. Braun and Clarke (2019) [47] highlight that thematic analysis is reflexive, with researcher subjectivity considered an asset to the process rather than a potential threat. Themes which represent meaning in the data are actively and creatively generated by the researcher. This contrasts with the view that knowledge is discoverable and that themes emerge passively from the data. Whilst reflexive thematic analysis is a flexible approach, for transparency, Braun and Clarke (2019) [47] emphasise the importance of stipulating the choice of theoretical underpinning. This study had an inductive orientation, with analysis driven by the data rather than a deductive approach which seeks to map the data onto an existing framework. The epistemological underpinning of the study was a social constructionist approach which assumes that reality is socially constructed and subjective, with individuals interpreting experience according to their own framework of knowledge [48]. Multiple and contrasting realities can therefore be linked to any experience. Whilst this applies to participants' experiences of the implementation of REACT, it is also relevant to the researcher’s interpretation of the data as context and subjectivity contribute to the process of meaning making.

2.2 Participants

Potential participants were relatives (including friends and partners), of service users in contact with EIP services across the six NHS Trusts in England participating in the IMPART study. Trusts were selected to achieve a sample representing geographic and ethnic diversity and anonymised through the allocation of bird habitat pseudonyms: Marsh; Ocean; Seashore; Moor; Woods; Lakes. Relatives were introduced to REACT by EIP staff in accordance with the IMPART protocol [25]. Three hundred and ten relatives were invited to access REACT across the Trusts, with 159 relatives creating a REACT account.

2.3 Recruitment

When relatives accessed REACT for the first time they were asked to consent to being interviewed. They were then contacted by email or telephone and provided with brief details of the interview, rationale and process. The Participant Information Sheet and Consent Form (See Ethics Section, Appendices 4B and 4C) were emailed to those who expressed interest and a face-to-face or a telephone interview was arranged for those who confirmed they were happy to participate. All participants had the opportunity to use REACT for at least a month before being interviewed.

The recruitment process was amended after 11 interviews had been conducted in order to allow members of EIP clinical staff to contact relatives who they had invited to use REACT, but who had not proceeded to access REACT and create an account. This amendment allowed exploration of the reasons behind the relatives’ decisions for choosing not to access REACT. From this point, focus groups were offered to relatives as an alternative to individual interviews but were not taken up.

2.4 Data collection

Over the 12-month study period, 23 interviews were conducted, 11 of which were conducted by the author (JB)[1]. Interviews took place over the telephone or face-to-face in NHS clinical locations and lasted between 40 and 70 minutes. Interviews were flexible and focussed around topics outlined in an interview topic guide (see Ethics Section, Appendix 4D). Prior to each interview, the Participant Information Sheet (see Ethics Section Appendix 4B) was discussed, with further opportunity for the relative to ask questions, and a consent form (see Ethics section Appendix 4C) was signed. All interviews were audio recorded and transcribed.

2.5 Analysis

Data analysis followed the six phase procedure proposed by Braun and Clarke (2006) [46]. The generation of themes is an active and creative process, with the researcher's subjectivity considered central to this [47]. Attention to reflexivity was rigorous to maintain awareness of assumptions, biases and contextual factors which contributed to the creation of meaning from the data. This was achieved through articulating expectations for the data prior to collection and analysis; noting on-going reflections in a journal, and regular supervision. My personal involvement with the development of the REACT intervention was identified as a key potential influence on the research process, as the time I had invested in REACT translated into a strong hope that it would be well received by relatives. Awareness of this helped to maintain balanced focus on both negative and positive feedback about REACT whilst analysing the interview data. My experience of working in mental health services as a trainee Clinical Psychologist meant that I had insight into the demands on services and the potential difficulties involved with implementing a new intervention. Engagement in clinical

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[1] 12 interviews were conducted by members of the IMPART Team as follows: EL (Research Assistant, Lancaster University), 1 interview; PO (Research Assistant University College London), 2 interviews; CM (Research Assistant, University College London), 8 interviews; BG (Research Assistant, Lancaster University, 1 interview.

and research activities at the same time emphasised the importance of addressing implementation issues and enhancing understanding of the knowledge-practice gap. This impacted the analysis as my experience of the clinical context assisted me in visualising the descriptions of participants, giving depth to the generation of the themes. Personal experience of informal caregiving meant that some of the accounts of the participants resonated with me, and the effect of this highlighted the subjectivity involved in the creation of themes. In addition, collaboration with two peer researchers who are relatives of people with psychosis added an experienced caregivers' perspective to the analysis and consideration of reflexivity.

The first phase of analysis involved thorough immersion in the data through reading the entire data set of transcribed interviews several times. Significant time was devoted to familiarisation, with notes about ideas and meanings attached to the data recorded.

The second phase involved examining the annotated transcripts and organising ideas about segments of the data into codes which represented areas of meaning. The entire data set was worked through systematically, with all potential codes marked in the margin of each transcript. The coding process was regularly reviewed through supervision, to support the reflexive process.

The next phase involved taking a broader perspective on the data and grouping the codes into patterns of meaning and potential themes, represented by a visual map. Potential themes and subthemes were elaborated, together with supporting quotations from the transcripts. Stages four and five comprised of an iterative and detailed process of reviewing and refining the themes. Reflections centred around the meaning of the themes, whether the coded data supported each theme, and the scope of each theme, with themes divided or amalgamated as needed. The names given to the overarching themes were considered to ensure that they accurately captured the sense of each theme's identity. The final phase of the analysis involved drafting the findings, including selecting illustrative quotations for the themes, and creating a narrative to convey the story of the data and its meaning in relation to the research question.

3. Results

3.1 Participant characteristics

Twenty-three relatives participated (all of whom had access to the internet at home). Table 1 summarises the demographic characteristics of the sample.

[INSERT TABLE 1]

3.2 Thematic analysis

The final thematic analysis elicited three overarching themes as key concepts in understanding the factors which impacted relatives' engagement with REACT. The themes, with their associated subthemes are summarised in Table 2.

[INSERT TABLE 2]

3.2.1 Theme 1: Motivation to understand and be understood

The first theme captures the factors impacting participants' initial decision about whether to access REACT. Understanding how participants' motivation is derived is fundamental to making sense of how relatives engaged with REACT as a pivotal first step in the process. The subthemes combine to illustrate that positive motivation to explore REACT is underpinned by participants' perception that the impact of the caring role is understood, and that this is reflected in both the content of REACT and the characteristics of the initial introduction to it.

The need to understand

All the participants provided rich detail about the experience and effects of caring for a family member, describing their reaction to the onset of their relatives' difficulties as a state of shock, accompanied by fear and uncertainty. This highlights the trauma associated with the onset of psychosis or bipolar disorder. One participant described how she felt “lost”, evoking a sense of isolation and a lack of clarity about what was happening. In addition to physical demands of time and energy, the emotionally traumatising impact of shock suggests that the participant’s ability to seek support and process information at this time would be limited, despite this being a real need. The acute need for signposting to a source of accurate information in an accessible format was highlighted.

“I think initially it was a tremendous shock and very frightening and we were just lost…I think that is a time when relatives or friends need oh really strong support you know and to be explained how the whole thing works.” (Seashore-RE-06).

“You just don’t know what it is and what’s it supposed to be, what’s supposed to be happening and there’s a real need for just quite simple information that you can trust, and you’re scanning the internet and you don’t really know what’s right and wrong at that point.” (Woods-RE-07).

“But I think the difficulty is I knew little or nothing about psychosis before he had it.” (Marsh-RE-03).

Participants described their lack of understanding about what was happening to their relative in terms of their illness, and the emotional impact of this uncertainty. One participant conveyed how all her resources in terms of time and energy were directed towards her relative, which left little space for understanding what was happening to the whole family. This created the sense that the immediate crisis was being attended to as a state of emergency, with no opportunity to take any perspective on the problem and analyse it. However, despite the lack of emotional space to understand the situation, there was a strong desire to make sense of it and understand its origins.

“It was very, very difficult to understand what was going on and where it had come from and you were just so confused and because you’re having to deal with it you don’t have any space to process it or to understand it.” (Woods-RE-08).

Despite extensive attempts to find someone who could tell them what they should do to support their relative, participants were often very frustrated about the lack of support and information available. Participants described the time and effort involved with physically travelling to different clinics and still not receiving any help or information. The sense of being excluded from services and the tenacity required on their part to even identify where it might be provided was palpable.

“I said literally I’ve walked (borough) and I’ve gone to one clinic after another and nobody can actually tell me how I get into the system.” (Seashore-RE-13).

The ongoing nature of the trauma highlighted by participants who describe the state as enduring for a long period of time, and the effect of this strain over months and years is significant. Participants spoke about the negative impact on their own mental health and stress levels. The intensity and all-encompassing nature of the caring relationship was exacerbated by uncertainty about the relative’s behaviour and the need for constant vigilance.

“You just don’t know from, you know, hour to hour really how they’re going to behave.” (Woods-RE-06).

“Because it’s so crazy for two years, trying to get support for him, and I was thinking, I’m going to end up having a mental breakdown.” (Seashore-RE-11).

Participants discussed difficulties with balancing the needs of the rest of the family due to the demands of the family member experiencing mental health problems. Challenges associated with allocating time to different roles such as wife or husband, friend, employee and parent to other siblings were described.

"Yes, you're not just the carer really, it's balancing everybody else's need in, 'cos that's the reality of families isn't it." (Marsh-RE-03).

*"I ended up being off work with him until April, so you know, there are big chunks of my life where I've had to take time out from what I do to care for *son*."* (Moor-RE-09).

Meeting our needs

When being introduced to REACT, participants needed to hear a description of its benefits as part of the introduction to confirm that it met their needs for information and support. They wanted explicit detail of what was covered in REACT and specifically how this could be of value to them. Key to this was a clear message that REACT prioritises the needs of the relative. The opportunity to hear stories from other relatives about their experiences was a key motivator to engage, especially when this was explicitly linked to reducing the sense of isolation which can accompany being a caregiver.

"And get it explained to them as well what they'll get from it, not just she says it's REACT and you might think oh great, how can it help. But if you can have it explained to them that they will witness other people, they're not the only person." (Moor-RE-10).

"That it was just so important for me to look after myself because I was his primary carer, you know that role was explained to me as well… I think it was after the second visit that (Care coordinator) sent me the contact details or the user details for me to log on to the REACT website." (Marsh-RE-08).

An empathic introducer

The personal characteristics and the relationship between participant and REACT introducer were significant in influencing the decision about whether to access REACT. Positive experiences of being introduced to REACT featured introducers who showed empathy and understanding about the circumstances and needs of the caregiver. The sense that the introducer had the participants' best interests at heart was fundamental. The significance of this positive interaction was emphasised by the contrast with participants' previous experiences of feeling excluded, confused and isolated when interacting with other services at the onset of the relatives' difficulties.

"I would go with anything that (care coordinator) had said and the person that worked with him previously, you know they were very good and they just wanted to help." (Seashore-RE-04).

A positive experience of interacting with the EIP in general, coupled with a strong individual relationship with the introducer appeared to be a key factor in deciding whether to engage with REACT. Strong individual relationships emerged when participants felt that they were being listened to, taken seriously, and not dismissed.

"But it was the Thursday of that week that the people from the EIP team first came, and I have to say they were absolutely brilliant. They spoke to me first, they were very concerned about how I was coping." (Marsh-RE-08).

Participants emphasised that they saw REACT as something which worked in conjunction with EIP, rather than being a replacement, with a strong existing relationship with EIP being important for this dynamic and REACT viewed as part of a package of care.

"If you've got the toolkit, I mean it doesn't replace the actual contact with the professionals, you know, that was invaluable, and still is actually. But it is useful in addition." (Ocean-RE-05).

Discussions were had with some of the participants about how they would feel about being introduced to REACT by another relative rather than a member of EIP staff. Feedback about this was positive, with participants highlighting the importance of understanding the actual experience of being a caregiver. This is significant as the participants' need for REACT is underpinned by a desire to understand the best ways to support their relative, in the form of helpful strategies and perspectives. Other caregivers in similar situations were viewed as capable of providing this support.

"I think if you're actually experiencing the problem yourself, you really have a better, you really understand what's useful and what's not useful." (Ocean-RE-05).

Immediate need

Participants emphasised that REACT should be available as soon as possible, to address the need for clarity and support during the early phase of their relatives' difficulties. Several participants expressed frustration that REACT had been offered too late to be of use to them. This indicated that the trauma of the new and shocking situation could have been helped by information or details about where to find support. This subtheme resonates with participants' accounts of their experiences at the onset of their relatives' difficulties, in that they described feeling lost and in darkness which reinforces the feeling of isolation, with no means of navigating through the situation.

"I do think the website itself is brilliant, but it was probably just too late for us." (Moor-RE-04).

"You're sort of there stumbling around in the dark really, so at that point initially if you're given information or signposted to things, I think then you can start to then understand ok what they're going through and all the rest of it." (Woods-RE-08).

Some participants acknowledged that too much information early on might have been experienced as overwhelming, but they still wanted REACT to be available for when they felt ready to engage.

"I mean I suppose for me it would have been valuable to give that information when I got a carers' pack. Even if you don't use it, basically you've got it, you know you can look at it." (Marsh-RE-03).

3.2.2 Theme 2: Personal relevance sustains engagement

The second theme represents the next step in the trajectory of engagement with the intervention, following the initial decision to access REACT. Participants' interest and ongoing engagement with REACT was underpinned by an evaluation about the extent to which the content was personally relevant and met their specific needs.

Experiential similarity alleviates isolation

Participants were positive about REACT's video clips, which illustrate examples of situations faced by other relatives and how they dealt with them. Specifically, the video clips were helpful in suggesting new strategies and ways of communicating with their relative, for example when experiencing scenarios such as hearing voices. REACT was viewed as enabling participants to change their perception and increase understanding of what their relative is experiencing through putting themselves in their shoes. Participants who were positive about the video clips showed relatively high levels of engagement in terms of the time they spent on REACT (see Table 1: Characteristics of participants).

"I found the information on there absolutely brilliant … because some of the people were even talking about the same experiences that I was having, so that made it feel, the videos were brilliant, and even the written information about how to react, how to deal with someone who's got a firm belief in you know an alternative reality." (Marsh-RE-08).

Relatives also explained how watching the video clips reduced their feelings of isolation, as they were able to identify with people in similar situations. This resonates with participants' accounts of feeling alone and lost at the onset of their relatives' difficulties, and suggests that in mitigating this isolation, the video clips are a key engagement factor for REACT.

"Yeah, I thought it was good because you could see real people, I know that weren't the actual people, but they were talking about the frustrations and you sort of didn't feel quite as

isolated, and so the simple things which could become very frustrating, how well they dealt with issues, that was interesting." (Ocean-RE-05).

Participants described how hearing personally relevant information about their relatives' condition from other caregivers increased their sense of confidence and empowerment. When participants interacted with clinical services, the information they received from REACT meant that they felt more equipped to have meaningful conversations and were not dismissed. Participants described how having more knowledge about their relatives' experiences has the potential to address the sense of being isolated and confused when searching for answers from external sources.

"I felt empowered honestly after having that little session online by myself, I felt really empowered by it." (Seashore-RE-09).

Information gaps

Participants disengaged from REACT when it failed to meet their needs for information that they could make specific to their relative, in order to understand their relatives' experiences and provide better support. This need is underpinned by the desire for personally relevant information which can be translated into new strategies and approaches to problems. This resonates with the first subtheme where positive responses to the video clips increased understanding and new ways of relating and illustrates the contrasting case. This highlights the importance of participants' judgement about personal relevance and potential practical application when deciding whether to continue to engage with REACT. Participants highlighted that they would like to see more information in REACT about medication and its side effects, and advice about how to act if needed.

"Explain the medication, explain the risk of the medication, you know because there's certain medication, often I do research about it, where there is a lot of side effects, addiction to it (the medication), my brother put on about four stone in weight within a short period of time

because of the medication, nobody told me about that, but how can a family member protect their family member if they don't know that information?" (Seashore-RE-11).

Some participants stated that REACT did not feel relevant to them, as it does not cover situations where the service user has more than one condition. This links with the idea that participants need to feel that REACT can be applied to the specifics of their situation and family.

"I mean I don't know how many people with psychosis may be on the autism spectrum, but my son was diagnosed last year, and a lot of parents I've spoken to have said the same thing." (Marsh-RE-03).

Most participants were parents, and the view was expressed that REACT lacked sufficient information about supporting sons or daughters to achieve an independent and fulfilling life. Participants also voiced concerns about what would happen if they were no longer around to support their child, and that this contributed to the need to support them to be independent. This emphasises the importance of participants' need to tailor the information provided in REACT to their individual situation in order to provide practical strategies for navigating through problems.

"Independence to me means … managing the things you have to do every day to be able to live independently." (Marsh-RE-03).

3.2.3 Theme 3: Usability and interaction enhance engagement

This theme captures the aspects of REACT's functionality which impacted participants' engagement. Factors which discouraged participants from using or returning to REACT include technical barriers which created access problems. However, participants who did not experience access problems found REACT easy to navigate and its modular format was positively received. Participants were disappointed by the lack of activity on the forum area of REACT, as this was considered an attractive feature which would have supported ongoing engagement.

Technical problems

Participants expressed frustration with the log on process for initially accessing REACT, describing how persistence and additional support from EIP staff was needed in some cases. Participants also spoke about on-going issues with accessing REACT. In some cases, technical difficulties meant that REACT was perceived as another task, or a problem to overcome, rather than a source of support. Frustration added to their feelings of stress and burden rather than helping. In one case, a participant referred to REACT as not liking them, which evokes an antagonistic relationship and a direct contrast with REACT's aim of providing support.

"So, I do need to be able to get on it easily 'cos that's like another oh God not something else I've got to do." (Marsh-RE-03).

"No, I don't know why it doesn't like me." (Marsh-RE-10).

Ease of navigation

Participants reported that REACT was easy to navigate and understand, with the colours and format considered attractive. The modular structure allowed some participants to identify which section of REACT was most relevant to them, and others to work through REACT methodically and sequentially. The fact that participants responded well to having the ability to identify for themselves which module to visit emphasises the idea that participants appreciated having autonomy and choice in their use of REACT, also seen in the subtheme about the timing of the introduction to REACT.

"Oh yeah well I thought it was bright, and like I say the big boxes to click on to send you further into what your wanting, really easy, and it's easy to navigate from one to the other, you know you can bounce around it, you don't have to go step-by-step anywhere, so you can

take bits whenever you want it, so yeah I found it quite user friendly and easy on the eye." (Moor-RE-09).

Inactive forum

Participants considered a well populated and fully functioning forum to be an attractive feature, as it would facilitate connection and communication between people in similar situations. This links with the positive views expressed about the video clips in that they facilitated identification with other relatives and the adoption of new strategies and perspectives. In addition, it was considered that a forum would provide motivation to revisit REACT, as new posts or replies to posts would represent a renewal of content. However, the lack of posts on REACT's forum discouraged participants from posting as they felt this would make them conspicuous. Data is not available on how many relatives engaged with the forum at each Trust, but feedback from staff across all Trusts indicates that this was very low.

The lack of forum activity also had the impact of detracting from the value of REACT as it was perceived as an aspect of REACT that was not functioning as it should, therefore reduced confidence in the rest of the intervention. Participants described how they checked the forum several times, and then followed this up by contacting EIP staff about whether the forum was active. This persistence demonstrates the level of interest and need for this feature.

"*The only thing I was slightly disappointed in was the forum, I mean I don't know how new the website is but there was just nothing on it, you know I was hoping to be able to just go in there and read what had been happening and how other people had dealt with them."* (Marsh-RE-08).

4. Discussion and conclusion

4.1 Discussion

This study aimed to identify the factors which impacted relatives' engagement with REACT. The analysis resulted in three overarching themes which capture the most significant factors affecting relatives' recruitment, enrolment and use of the intervention: (i) motivation to understand and be understood; (ii) personal relevance sustains engagement; and (iii) usability and interaction enhance engagement. There is a lack of qualitative research covering end users' perspectives on the complete process of signing up to and engaging with DHIs [42], and this is needed to enhance understanding of the evidence-practice gap relating to their adoption and integration. The findings from this study have direct implications for the implementation of REACT but also useful points of learning for implementation plans for other DHIs for mental and physical health conditions.

Understanding the context experienced by relatives is fundamental to the implementation of REACT, as it impacts each stage of the enrolment and engagement process. The key driver motivating relatives to engage with REACT was the need to understand the situation they were facing and to learn how they could cope with this.

The perception that relatives' needs were understood and met by REACT drove the initial motivation to access the intervention. This is conveyed through the introduction to REACT which is underpinned by the necessity of understanding the relatives' situation, both generally in terms of the common stresses faced by caregivers, and individually, with focus on the specific relative's needs. Acknowledgement that relatives' resources are stretched due to their caring responsibilities means that the value of REACT must be communicated by introducers in order support the decision to enrol. This fosters a strong relationship between introducer and relative, and consequently the relative is more likely to trust the introducer and their recommendation of REACT. The question of when REACT should be introduced also demonstrates the necessity of understanding the challenges experienced by relatives, as participants stated that they would like to receive REACT as soon as possible, whilst maintaining autonomy about deciding when the optimum time is for them to engage.

A successful introduction to REACT is underpinned by a demonstration of empathy for the relatives' situation, and this positive support should continue through prompts to use REACT or help with tailoring its content to individual needs. This has implications for the development and implementation of other DHIs, as it suggests that self-management interventions designed to be used with support are likely to be more positively received by end users than interventions which feature no support. Effective support provided by a trusted clinician has the potential to mitigate users' low hypothetical acceptability of DHIs [32] by addressing fears and preconceptions about DHIs and highlighting the benefits and usability. This is consistent with research indicating that allowing time for discussions between clinicians and users about the DHI at the time of introduction is a key part of the implementation process [49].

Sin and colleagues' review [26] of DHIs for caregivers of people with chronic health conditions noted that caregiver access to clinicians, advisors or experts was available in 27% (17) of the interventions identified, with a further 15% (9) of interventions featuring scheduled contact with advisors or experts. The importance of clinician contact highlighted by this study appears significant for implementation plans for DHIs as less than 50% of interventions identified by Sin and colleagues [26] featured this. However, the underlying nature of each DHI will affect the appropriateness of integrated clinician support.

The importance of human and interactive factors is also illustrated by participants' experiences of the video clips which feature in REACT, and the forum. Video clips were positively received as they enabled relatives to identify with other caregivers through hearing their stories, and the lack of forum caused frustration and disengagement as it was considered a strongly appealing feature of REACT. Relatives appreciated it when REACT was personally relevant to them and facilitated learning new strategies and perspectives on problems from other relatives in similar situations. This has implications for other DHIs as it suggests that including examples from other service users has the potential to support behaviour change, reduce isolation and alleviate distress.

Participants expressed the desire to connect with other relatives through the forum for similar reasons, and a forum which facilitates communication and the exchange of ideas appears to be a desired element of a DHI. A recent study found that a higher burden of distress attributable to a caring role was associated with greater use of a DHI which provided social support [50], highlighting the potential for social interaction to attend to the needs of caregivers. Inclusion of a forum therefore requires consideration in the development of the DHI and highlighting in its introduction to the end-users. However, lack of activity on the forum proved a barrier to engagement.

A further implication from the finding that a forum facilitating interaction between users is a positive engagement factor, is that it could potentially mitigate one of the barriers to engagement expressed by participants. Participants disengaged from REACT when they felt it was not relevant to them through not being specific enough to their needs and whilst there are commonalities in the experiences and impact of caring, each caring relationship is unique with different priorities at any point in time. Issues such as co-morbidity, medication and side effects and supporting recovery were highlighted as prominent for certain participants. A forum which enabled relatives to ask questions about specific difficulties could have addressed this issue, been beneficial to relatives and supported ongoing engagement with REACT [51].

A barrier to engagement with REACT surrounded the difficulties some participants experienced with accessing REACT, logging on and creating an account. This resonates with previous research highlighting that the ease of use of the underlying DHI is a key engagement factor [39, 52]. This also implies that whilst DHIs have the potential to provide cost-effective care, the amount of initial investment required to develop and test the intervention rigorously to ensure functionality should not be under-estimated. Research indicates that the development and testing of DHIs should incorporate user perspectives to ensure that the content is beneficial, relevant to lived experience and consistent with values [53]. User-centric design has been highlighted as key to the development of DHIs [54-56].

4.2 Strengths and limitations

Key strengths of this study are its coverage of the process of signing up to, accessing and using a DHI; its exploration of the impact of service level implementation activities on the end user of the DHI; its inclusion of participants from geographically diverse NHS Trusts and its emphasis on the importance of user perspectives in designing an implementation plan for a DHI.

A key limitation is bias in the sampling of participants. All participants had access to the internet at home; the majority were female and mothers of service users; all were relatively engaged with EIP services; and all were English speakers. The fact that all the participants had access to the internet at home implies that one of the identified barriers to engagement with DHIs highlighted in previous research has already been overcome – online access and a certain level of technical competence [49]. This means that REACT potentially excludes caregivers who are unable or unwilling to access support and information online, which could compound the isolating impact of caring and further marginalise this group.

All the participants were engaged with EIP and the majority were positive about services provided, and this underpins a willingness to try REACT in the context of the EIP offering. However, this raises the issue of excluding the provision of support to relatives who are struggling to access the system. One implication of this study is that REACT works well in tandem with support from EIP services, but that relatives who have not engaged with clinical teams may be excluded from benefiting from REACT if it is delivered in this format, and are likely to be experiencing the burden indicated by research [8, 11] and the findings of this study.

Whilst the intention had been to interview participants from all the 6 NHS Trusts participating in the IMPART study, this was not possible as it was dependent on implementation activities in each Trust. No relatives were recruited for interview from one NHS Trust and it would have been insightful to have spoken to relatives in this Trust to understand their experiences of how REACT was implemented. Despite extensive efforts to recruit participants who decided not to access REACT to explore their reasons for this, it proved challenging. Three relatives in this category were interviewed, and further research to identify engagement factors at this initial stage in the implementation process would be valuable [49]. In addition, whilst a functioning forum was highlighted as an engagement factor which would motivate relatives to continue to access REACT over time, further exploration of the factors which support on-going engagement and address questions about the lifespan of a DHI would be informative.

4.3 Conclusion

The factors identified as impacting relatives' engagement with REACT have transferable implications to the development and implementation of DHIs, which is pertinent in view of UK government initiatives to incorporate healthcare technologies in the delivery of care for long-term conditions [41, 57]. A well-functioning intervention which represents a comprehensive reflection of the needs of the end user is the essential foundation of an implementation plan. This study also suggests that human visibility and interaction, both from clinical staff and with other users, is key to engagement. This indicates that well supported self-management DHIs which facilitate identification with and connection between users are more likely to be adopted and successfully implemented into routine clinical care. The provision of appropriate support to introduce and accompany a DHI, establishing an effective online forum and embedding examples of other service users' experiences in a digital offering all require a thorough understanding of the needs of the end-user, as strongly emphasised by the participants in this study.

4.4 Practice implications

Involving service users and caregivers at each stage of the design and implementation of DHIs is fundamental to gaining an understanding of the needs of the end-user. Ensuring that both content and delivery of the DHI reflects this understanding appears to be a key factor underpinning engagement.

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Tables:

Table 1: Characteristics of participants

Participant ID	Age Group	Gender	Ethnic Group	Employment	Caring Relationship	Time on REACT (minutes)
Woods-RE-06	51-55	Female	British	Part-time	Mother	99
Woods-RE-07	56-60	Female	British	Part-time	Mother	78
Woods-RE-08	56-60	Female	White and Black Caribbean	Unemployed	Mother	10
Moor-RE-04	16-20	Female	British	Full time	Sibling	70
Moor-RE-09	46-50	Female	British	Part-time	Mother	93
Moor-RE-10	51-55	Female	British	Part-time	Mother	63
Moor-RE-11	46-50	Male	British	Full-time	Father	0
Ocean-RE-05	46-50	Female	British	Part-time	Mother	298
Ocean-RE-06	51-55	Female	British	Full-time	Mother	62
Seashore-RE-04	56-60	Female	British	Part-time	Mother	14
Seashore-RE-05	41-45	Female	Other White background	Unable to work due to caring responsibilities	Mother	22
Seashore-RE-06	66-70	Female	British	Retired	Mother	63
Seashore-RE-09	36-40	Female	Caribbean	Unable to work due to caring responsibilities	Mother	114
Seashore-RE-10	61-65	Male	British	Part-time	Father	41
Seashore-RE-11	31-35	Male	Indian	Full-time	Sibling	15
Seashore-RE-12	50-56	Female	Asian or Asian British: Indian	Full-time	Mother	0
Seashore-RE-13	66-70	Female	British	Retired	Mother	61
Marsh-RE-03	61-65	Female	British	Retired	Mother	89
Marsh-RE-08	61-65	Female	British	Retired	Mother	266
Marsh-RE-09	51-55	Female	British	Unemployed	Mother	35

Marsh-RE-10	61-65	Female	British	Full-time	Mother	37
Marsh-RE-11	56-60	Female	British	Unable to work due to ill health	Mother	15
Marsh-RE-12	46-50	Female	British	Full-time	Mother	0

Table 2 – Key themes in understanding participants' engagement with REACT

Theme 1 MOTIVATION TO UNDERSTAND AND BE UNDERSTOOD	**Theme 2** PERSONAL RELEVANCE SUSTAINS ENGAGEMENT	**Theme 3** USABILITY AND INTERACTION ENHANCE ENGAGEMENT
The need to understand	Experiential similarity alleviates isolation	Technical problems
Meeting our needs	Information gaps	Ease of navigation
An empathic introducer		Inactive forum
Immediate need		

Appendix 1A: Patient Education and Counseling Author Information Pack

PATIENT EDUCATION AND COUNSELING

Official journal of EACH, the International Association for Communication in Health Care and AACH, the American Academy on Communication in Healthcare

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

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DESCRIPTION

Patient Education and Counseling is an interdisciplinary, international journal for **patient education** and health promotion researchers, managers and clinicians. The journal seeks to explore and elucidate the educational, **counseling** and **communication** models in **health care**. Its aim is to provide a forum for fundamental as well as applied research, and to promote the study of organizational issues involved with the delivery of patient education, counseling, health promotion services and training models in improving communication between providers and patients.

Patient Education and Counseling is the official journal of the International Association for Communication in Healthcare (EACH) and the American Academy on Communication in Healthcare (AACH).

Manuscript Submission

The journal welcomes unsolicited manuscripts related to the field of patient education, counseling and clinical health promotion and communication in medicine. During submission, authors can select a category from the list below. The type of manuscript should be indicated in the cover letter.

Original Articles - Preference is given to empirical research which examines such topics as adherence to therapeutic regimens, provider-patient communication, patient participation in health care, degree of social support, decision-making skills, anxiety, physiological changes, or health/functional status. Maximum 4000 words. Please note that manuscript wordcounts EXCLUDE the following in the count: Abstract, acknowledgements, references, tables, figures, conflict of interest statements. Both descriptive and intervention studies are acceptable.?

Review Articles (Current Perspectives) - In-depth reviews of the empirical research in one facet of the patient education and counseling including an analytical discussion of contemporary issues and controversies in patient education and counseling (maximum 5000 words not including references and tables).

Educational Model of Health Care - Case studies of innovative programs which exemplify the educational model of health care, for example, self-care groups, patient advocacy efforts, medication self administration programs and co-operative care units (maximum 2000 words not including references and tables).

Short Communications - in any of the above categories will also be considered (maximum 1500 words not including references and tables).

Reflective practice - The Reflective Practice section includes papers about personal or professional experiences that provide a lesson applicable to caring, humanism, and relationship in health care. We welcome unsolicited manuscripts. No abstract is needed. No (section) headings, no numbering. Maximum 1500 words. First name and surname of the author and his/her institution affiliation address, telephone and fax number and e-mail address where the corresponding author can be contacted, title of the papers and text. Submissions will be peer-reviewed by two reviewers. For further information on the Reflective Practice section see: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. Patient Education and Counseling 2004; 54:251-253.?

Medical Education - Articles on medical education focus on educational efforts that target experiences, programmes and educational research on the teaching/training and evaluation of interpersonal/communication skills of health care providers and their attitudes and skills needed for optimal communication.

Please submit your article via http://ees.elsevier.com/pec/

AUDIENCE

Patient Education Researchers, Managers and Counselors, Health Educators and Health Care Providers, Psychologists and Sociologists, concerned with information, education and counseling of patients.

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ABSTRACTING AND INDEXING

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PubMed/Medline
Current Contents - Clinical Medicine
Sociedad Iberoamericana de Informacion Cientifica (SIIC) Data Bases
CINAHL
Current Contents - Social & Behavioral Sciences
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GUIDE FOR AUTHORS

PEC Aims and Scope

Patient Education and Counseling is an interdisciplinary, international journal for patient education and health promotion researchers, managers, physicians, nurses and other health care providers. The journal seeks to explore and elucidate educational, counseling and communication models in health care. Its aim is to provide a forum for fundamental as well as applied research, and to promote the study of the delivery of patient education, counseling, and health promotion services, including training models and organizational issues in improving communication between providers and patients.

Patient Education and Counseling is the official journal of the European Association for Communication in Healthcare (EACH) and the American Academy on Communication in Healthcare (AACH).

PCI Aims and Scope

PATIENT-CENTERED INNOVATION
International. Interdisciplinary. Practical.

Patient-Centered Innovation is an online, peer-reviewed, special feature of *Patient Education & Counseling* (PEC), launching in 2018. Content will focus on work that brings patient perspectives into the design, implementation, and evaluation of interventions intended to improve health and transform health care delivery. As part of PEC, articles in Patient-Centered Innovation will be indexed in Medline/PubMed.

Innovation requires ideas *and* execution: It involves a disciplined process of defining problems to be solved, developing solutions for transformational change, implementing solutions, and measuring impact. Ideally, patient-centered innovation embraces patient perspectives in problem definition and solution design, and measures impact in terms of outcomes that matter to patients. The scope includes the full range of interpersonal, group, mediated, and technology-enabled innovations and interventions.

By focusing on user-centered design and innovation with practical value, *Patient-Centered Innovation* aims to advance the pace and sustainability of meaningful change in areas such as care coordination, communication, health care encounters, medical and health professional education, patient activation, patient experience, patient and family engagement, patient involvement, patient-reported outcomes, relationship-centered care, remote monitoring, resilience, self-care, shared decision making, telehealth, and virtual access.

The Editorial Board will include patients and other laypersons, health professionals, innovation leaders, and social scientists. The editorial process will assess scientific quality of the work as well as relevance and utility to patients and health professionals in real-world settings. Robust use of established measures is encouraged unless there is clear need for a new measurement approach.

In addition to empirical studies on the outcomes of patient-centered innovation, thoughtful articles on innovation design and development, innovation capacity and sustainability, patient-centered research design, feasibility studies, and/or negative findings are welcome, as they can be instructive for others in the field. In an effort to build a coherent literature base and common vocabulary, *Patient-Centered Innovation* will include editorials and primers with essential background and context.

Please see the Author Instructions for more information on submission guidelines.

Gregory Makoul PhD MS (United States) will serve as Editor-in-Chief, with Sara Rubinelli PhD (Switzerland), Angela Liu PhD MBA (China), Sandra van Dulmen PhD (The Netherlands), Jon Vozenilek MD (United States), and Angela Zambeaux (United States) as Associate Editors.

PEC Manuscript Categories

During online submission, the author can select a category from the following list: Research Paper, Review Article, Short Communication, Reflective Practice, Discussion or Correspondence. The type of manuscript should be indicated in the cover letter.

Research Papers Preference is given to empirical research which examines such topics as provider-patient communication, patient education, patient participation in health care, adherence to therapeutic regimens, social support, decision-making, health literacy, physiological changes, health/ functional status etc. Maximum 4000 words. Please note that manuscript word counts EXCLUDE the following: Abstract, acknowledgements, references, tables, figures, conflict of interest statements. Both descriptive and intervention studies are acceptable. Each Research Paper will also require a heading selected from the following to identify the section of the journal to which it best applies: Communication Studies, Patient Education, Healthcare Education, Healthcare and Health Promotion, Patient and User Perspectives and Characteristics, Assessment and Methodology.
Review Articles In-depth reviews of the empirical research in an area relevant to the journal, including analytical discussion of contemporary issues and controversies (maximum 5000 words not including references and tables)
Short Communications Brief articles in any of the above categories will also be considered (maximum 1500 words not including references and tables).
Reflective practice We welcome personal narratives on caring, patient-clinician relationships, humanism in healthcare, professionalism and its challenges, patients' perspectives, and collaboration in patient care and counseling. Most narratives will describe personal or professional experiences that provide a lesson applicable to caring, humanism, or relationships in health care. No abstract is needed. No (section) headings, no numbering. Maximum 1500 words. Submissions are peer-reviewed.For further information, see the editorial published in PEC: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. Patient Education and Counseling 2004;54:251-253.
Discussion Forum - Papers in the Discussion Forum will include two categories: Discussion Papers up to 3000 words with discussion and commentary on relevant topics within the Aims and Scope of the journal. A Discussion paper should elucidate a theory, concept or problem in an area relevant to the journal.
Correspondence Papers (up to 1500 words) with brief comments on articles in previous issues of the journal.

Guidelines

We encourage authors to consult appropriate guidance, depending on the design of their study.For randomized trials, consult CONSORT (Consolidated Standards Of Reporting Trials) http://www.consort-statement.org/
For systematic reviews and meta-analyses consult PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) http://www.prisma-statement.org/
For statistical analysis and reporting, consult SAMPL (Basic Statistical Reporting for Articles Published in Biomedical Journals: The "Statistical Analyses and Methods in the Published Literature") http://www.equator-network.org/reporting-guidelines/sampl/
For qualitative studies, see specific editorials published in PEC: Finset A. Qualitative methods in communication and patient education research. Patient Educ Couns, Volume 73, Issue 1, October 2008, Pages 1-2. DOI: 10.1016/j.pec.2008.08.004
Salmon P. Assessing the quality of qualitative research. Patient Educ Couns Volume 90, Issue 1, January 2013, Pages 1-3. DOI: 10.1016/j.pec.2012.11.018
Salmon P, and Young B. Qualitative methods can test and challenge what we think we know about clinical communication - if they are not too constrained by methodological 'brands'. Patient Educ Couns Volume 101, Issue 9, September 2018, Pages 1515-1517. DOI: 10.1016/j.pec.2018.07.005

PCI Author Instructions

PATIENT-CENTERED INNOVATION

International. Interdisciplinary. Practical.

Author Instructions

In general, submissions to *Patient-Centered Innovation* should clearly reflect the Aims + Scope, with a focus on bringing patient perspectives into the design, implementation, and evaluation of interventions intended to improve health and transform health care delivery. The editors are particularly interested in submissions that highlight user-centered design and innovation with practical value that can advance the pace and sustainability of meaningful change in areas such as care coordination, communication, health care encounters, medical and health professional education, patient activation, patient experience, patient and family engagement, patient involvement, patient-reported outcomes, relationship-centered care, remote monitoring, resilience, self-care, shared decision making, telehealth, and virtual access.

As *Patient-Centered Innovation* is a special feature of *Patient Education and Counseling* (PEC), authors will use the PEC site for online submission. The first line of the cover letter must: (1) clearly state that the manuscript is being submitted for *Patient-Centered Innovation*; (2) clearly indicate the type of submission by choosing a category from the following list:
Research Articles - 2,500 words Review Articles - 3,500 words Invited Articles + Primers - 2,500 words Commentaries + Letters - 500 words

Authors must follow the category-specific instructions before submitting a manuscript. Research Articles, Review Articles, Invited Articles + Primers will go through a rigorous peer-review process to assess scientific quality as well as relevance and utility to patients and health professionals in real-world settings. All accepted and published submissions will be open to a constructive exchange of ideas with a diverse group of stakeholders.

Research Articles (2,500 words). Preference is given to empirical research that either sets the stage for patient-centered innovation (e.g., well designed feasibility studies) or measures the impact of interventions intended to improve health and transform health care delivery. Thoughtful articles on patient-centered research design and/or negative findings are welcome, as they can be instructive for others in the field. Robust use of established measures is encouraged unless there is clear need for a new measurement approach. All Research Articles should have a structured abstract of up to 300 words, using the following subheadings: Background
defining the problem to be solved Objective
testing the innovation intended to solve the problem Patient Involvement
outlining if/how patients were involved in problem definition, solution design or selection, and impact measurement Methods
making the process understandable and replicable Results
presenting major findings with appropriate, compelling visualizations Discussion
integrating results and implications, with attention to limitations, sustainability and spread Practical Value
clearly stating why the results of this study matter at a very practical level (i.e., answer the 'so what?' question) Funding
sources and role, if any, of the funding organization in the study and/or submission

While the SQUIRE Guidelines were constructed for quality improvement work, authors may find them helpful when constructing their submissions to Patient Centered-Innovation.

Review Articles (3,500 words). Given the variety and volume of work on innovation in health care, well-constructed reviews can be an extremely valuable contribution to the literature. Review articles should catalyze progress by highlighting overlap of, or conflict between, ideas and approaches. All Review Articles should have a structured abstract of up to 300 words, using the following subheadings:

Background
defining the problem to be solved Objective
specifying the scope of the review and the question it aims to answer Patient Involvement
outlining if/how patients were involved in the review process Methods
making the process understandable and replicable Results
presenting major findings with appropriate, compelling visualizations Discussion
integrating results and implications, with attention to limitations Practical Value
clearly stating why the results of this study matter at a very practical level (i.e., answer the 'so what?' question) Funding
sources and role, if any, of the funding organization in the study and/or submission

All systematic reviews and meta-analyses should follow the PRISMA Guidelines.

Invited Articles + Primers (2,500 words). In an effort to build a coherent literature base and common vocabulary, innovators may be invited to share lessons learned and/or essential background that can advance work in Patient-Centered Innovation. These may include articles on innovation design and development, innovation capacity and sustainability, health care delivery science, or useful definitions and approaches to work in the field.

Commentaries + Letters (500 words). The editors are very open to submissions - in the form of commentary on published articles, ideas for invited articles, and other correspondence to advance the field - from the full spectrum of stakeholders, including patients, caregivers, other laypersons, innovation leaders, health professionals, and social scientists.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

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BEFORE YOU BEGIN

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Policy and Ethics

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All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

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OR

(2) " I confirm that the patient/person(s) have read this manuscript and given their permission for it to be published in PEC".

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PREPARATION

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This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of one independent expert reviewer to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. More information on types of peer review.

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To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

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Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Manuscripts should be organized as follows:

Title page, Abstract, 1. Introduction, 2. Methods, 3. Results, 4. Discussion and Conclusion, References, Legends.

Discussion and Conclusion should be headed as one section and divided into three parts. Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

Introduction
State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods
Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Results
Results should be clear and concise.

Discussion and Conclusion

Discussion and Conclusion should be headed as one section and divided into three parts. Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

Practice Implications

Articles should include a paragraph or paragraphs entitled 'Practice Implications' as part of the discussion and conclusion, which outlines the implications for practice suggested by the study. Authors should take care that these implications follow closely from the data presented, rather than from other literature. In the event that an article presents very preliminary data or conclusions, these paragraphs may be omitted

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If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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Abstract

A structured abstract, by means of appropriate headings, should provide the context or background for the research and should state its purpose, basic procedures (selection of study subjects, observational and analytical methods), main findings (giving specific effect sizes and their statistical significance, if possible), principal conclusions and practice implications. Abstracts should adhere to the following format: **Objective, Methods, Results, Conclusion, Practice Implications. The word limit for abstracts is 200.**

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

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This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Units

Follow internationally accepted rules and conventions: use the international system of units (SI). If other units are mentioned, please give their equivalent in SI.

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Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

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[5] Cancer Research UK, Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/, 2003 (accessed 13 March 2003).
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Section Two: Literature Review

How do caregivers of people with mental or physical health conditions engage with online peer support?

Prepared for submission to *Patient Education and Counseling* [1]

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How do caregivers of people with mental or physical health conditions engage with online peer support?

Abstract

Objective: Caregivers of people with health conditions have a need for support and information due to the emotional, physical and practical demands of the caring role. Connecting with other caregivers online represents a potential source of support. Online peer support has evolved rapidly in a variety of formats covering a wide range of health conditions. The objective of this review is to synthesise qualitative literature about how caregivers of people with physical or mental health conditions engage with online peer support and explore the function it serves for them.

Methods: Electronic databases (CINAHL; Medline; PsychInfo; SocIndex and Web of Science) were searched to identify literature for inclusion. Findings of the included studies were analysed using a thematic synthesis.

Results: Thirty-four studies conducted between 2001 and 2019 were included. Included studies analysed data from online peer support platforms which were accessible to the public (n = 18) and research generated (n = 16) covering a range of mental and physical health conditions and caring relationships. Thematic synthesis resulted in two overarching themes which represent the function of online peer support for the participants: (i) meeting caregivers' needs for a new type of sustaining friendship; and (ii) creating a space to express uncomfortable emotions.

Conclusion: The review highlights caregivers' engagement with flexible, emotionally supportive and reciprocal interaction online underpinned by experiential similarity. Online peer support offers a safe space to express emotions away from the caregiving relationship. Caregivers find connecting online with peers beneficial in terms of social support, emotional support and the exchange of information which helps them in their caregiving role.

Practice implications: Online peer support has the potential to meet caregivers' needs for support and mitigate the impact of caregiver burden. This is aligned with clinical guidelines for supporting caregivers of people with mental or physical health conditions. Developing interventions which enable caregivers to connect with others who share common identities and experiences appears beneficial, with service user input valuable.

1. Introduction

1.1 Background

The provision of informal, unpaid care for a family member, friend or partner with a health condition is widespread. Between 2001 and 2015 the UK caregiver population grew by 16.5% to 6.8 million compared with general population growth of 6.2% during the same period [1]. Recent estimates indicate that the number of caregivers in the UK rose further to 8.8m in 2019 [2]. At the same time the amount of home care provided by local authorities fell, leading to a gap in provision which is filled by unpaid caregivers estimated as saving the UK £132 billion each year [1]. This pattern is repeated globally, with estimated reports of informal caregiver populations of 3.2 million in Germany, 8.3 million in France, 4 million in Italy [3] and 43.5m in the US [4]. An ageing population and increasing prevalence of chronic health conditions emphasise the key role of informal caregivers.

However, caring for someone with a mental or physical health condition can result in significant psychological, physical, practical and financial burden [5-8]. Distress associated with the caring role has been established across a range of physical and mental health conditions including cancer [9], Alzheimer's disease [10], stroke [11] and bipolar disorder [12]. Relationships impacted include parents and children [13], partners [14] and siblings [15].

Recent guidance [16] for supporting adult caregivers across all health conditions reviews interventions designed to provide psychological and emotional support and makes evidence-based recommendations that caregivers should be provided with group-based support. Beneficial effects of group-based interventions include reduction in the impact of caring and morbidity and improved levels of choice, control and efficacy [17-19]. Caregivers participating in group-based activities experience improved social support, reduced social isolation, and increased emotional awareness [20-22]. National Institute for Health and Care Excellence (NICE) (2020) guidance [16] highlights the importance of peer support for caregivers, which is underpinned by research demonstrating the key role of social support from people in similar circumstances in improving health related coping [23, 24].

However, the demands of caring mean that the logistics of accessing support can be challenging. Attending regular face-to-face carers groups is difficult to balance with work, family and other commitments in addition to caring responsibilities [25]. Perceived stigma about the caring role also impacts caregivers accessing support [26, 27]. Despite clinical guidelines which recognise caregivers’ need for support and stipulate that this be offered by services, levels of provision across mental and physical health conditions are low [28-30].

1.2 Online peer support

The internet offers a way of mitigating the challenges associated with attending face-to-face peer support and offers a flexible method of seeking information and support through connecting with people in similar situations. Ninety-three percent of UK households had access to the internet in 2019, with 87% of adults using it daily [31]. Healthcare related use of the internet continues to evolve; the number of adults in the UK searching for health related information online grew from 54% of internet users in 2018 to 63% in 2019 [31]. The NHS Long Term Plan [32] recognises the potential for integrating digital technologies with healthcare provision and there has been growth in the development of interventions using online platforms. Whilst online peer support is being incorporated into clinical interventions for caregivers across a range of health conditions [33-35], these often require that caregivers are in contact with services and may exclude those experiencing more acute social isolation.

There has been rapid growth in healthcare related support which is freely accessible via social media platforms, allowing people to obtain information, share their experiences online and interact with others experiencing similar health conditions [36-38]. A wide range of online peer support is available, including blogs where caregivers create content which reflects their experiences and invite interaction from other caregivers, and discussion boards or forums which bring together caregivers in order to communicate. Charities such as Carers UK have established discussion forums which are moderated to ensure that online community guidelines are adhered to, (www.carersuk.org/forum). The range of online support available offers choice and flexibility to connect with other caregivers and provides an anonymous space which mitigates restrictions imposed by time or geography. Asynchronous communication can reduce the pressure of face-to-face interactions and allows contributors to reflect on their input.

Online peer support for caregivers of people with mental and physical health conditions appears to be well received in terms of providing information and social support [39, 40]. Caregivers perceive emotional benefits such as decreased isolation, and practical benefits such as information which helps them to perform their caring role [41]. Hamm and colleagues [42] conducted a review of social media use amongst patients and caregivers across a range of conditions and found evidence for the utility of online discussion boards based on the findings of randomised controlled trials, where primary outcomes related to health behaviours including self-care and treatment adherence.

Online interventions featuring peer support have the potential to address caregivers' needs in a convenient, inexpensive and flexible format. However, whilst the effectiveness of online interventions has been widely researched, this has not translated into widespread dissemination and sustained use [43, 44]. A small sub-sample of people who are offered online interventions engage with them, and on-going usage levels are very low compared to face-to-face interventions [44]. However, there is evidence that higher levels of engagement are associated with greater improvements in outcomes including depressive symptoms [45], anxiety and mental well-being [46]. Therefore, it is important to understand the factors which impact engagement with online interventions in addition to evaluating their effectiveness [43, 44].

1.3 Focus of the review

This review focussed on enhancing understanding of caregivers' experiences of engaging with online peer support, and specifically examined what caregivers use online peer support for and the function it has for them. A broad perspective was taken to encompass physical and mental health conditions, which is aligned with NICE 2020 [16] guidance covering the support needs of caregivers across health conditions. Findings were synthesised from a range of data sources to capture online peer support provided in a variety of formats including peer support integrated with clinical interventions and peer support accessible to the public via social media. Greater understanding of the function fulfilled by online peer support affords clarity on caregivers' motivation to engage initially and remain engaged. The design of online interventions has been identified as a key factor impacting engagement [43], and knowledge which assists in developing interventions featuring peer support which meet caregivers' needs is invaluable. The findings of the review have potential to inform the development of online interventions incorporating peer support in order to facilitate high and sustained usage levels and deliver their intended benefits to caregivers.

2. Methods

2.1 Design

This systematic review was conducted using thematic synthesis [47]. Thematic synthesis is a method of integrating findings from multiple qualitative studies using thematic analysis. This method is aligned with the aim of the review as it was developed to address questions about people's experiences and perspectives in a health care context [47]. It is suited to synthesising in-depth qualitative findings and those which are less detailed [48]. Thematic synthesis is underpinned by a critical realist epistemological position, which assumes that knowledge of reality is mediated by an individual's perspectives and beliefs [48].

2.2 Search strategy

The search and selection of studies for inclusion in this review was carried out in September 2019. The inclusion criteria were established to identify papers focussing on (1) caregivers' use of online peer to peer support; (2) caregivers of people with mental or physical health conditions; (3) qualitative data. Advice was taken from a university academic liaison librarian regarding the search strategy. Databases were selected to provide breadth across psychology, healthcare and sociology settings and comprised of CINAHL, Medline, PsycInfo, SocIndex and Web of Science. The research question guided the selection of search terms representing three categories, "online" "caregiver "and "peer support." Searches did not specify a qualitative methodology in order to achieve a comprehensive search which would enable qualitative data within mixed methods studies to be included. Searches were limited to include English language papers published in peer reviewed journals from 1995 onwards. This date was chosen to capture the advent of peer support available through online platforms, as web-browsers were launched in 1993 [49] and 1995 was considered the earliest date that literature on the subject would start to proliferate. Key word searches were conducted with individual database subject headings using the Boolean operators “AND” and “OR” to combine or exclude sets of search terms. Please see Appendix A for search strategy details.

Database searches resulted in 1551 papers from CINAHL (417), Medline (367), PsycInfo (277), SocIndex (98), and Web of Science (392). The papers were collated using a referencing software program, which facilitated the identification of 700 duplicates and a final search result of 851 papers. Titles and abstracts of the papers were screened to determine appropriateness of inclusion. This resulted in 70 papers, of which the full text was screened. Thirty-nine papers were excluded through having a quantitative methodology (11); relating to online interventions with minimal or no peer support (18); presenting combined caregiver and patient data (9); and focussing on bereaved caregivers (1). Thirty-one papers were retained. The reference lists of the 31 papers were reviewed, following which 3 further papers were identified for inclusion. This resulted in a total of 34 papers for inclusion in the review. Figure 1 represents the systematic search process.

[INSERT FIGURE 1]

2.3 Quality appraisal

Two quality appraisal methods were used as, consistent with other thematic syntheses, a single appraisal tool which captures both the practical aspects of conducting qualitative research and the usefulness of the findings for the synthesis could not be found [50, 51]. The Critical Appraisal Skills Programme checklist (CASP) [52], was used to evaluates studies across 10 key practical aspects of qualitative research. The 10 questions cover the suitability of a qualitative method to the research aim; research design; data collection and analysis; ethics; the relationship between researcher and participants; and the value of the research. The CASP checklist is scored using 3-point rating scales [53]. For example, a high score (3) was allocated if data analysis was rigorous, a medium score (2) was allocated if data analysis was adequate and a low score (1) was considered appropriate where the description of data analysis was minimal. The second quality appraisal was adapted from a process outlined by Rees and colleagues [50] which focusses on the reliability and usefulness of the studies. This involved giving a high (score of 3), medium (score of 2) or low (score of 1) weighting to the reliability and the usefulness of each study. Questions appraising reliability concerned the rigour of data sampling, collection and analysis. Questions appraising usefulness focussed on the breadth and depth of the findings, the extent to which the findings were grounded in the data and privileged the caregivers' perspective.

2.4 Data analysis

Data analysis followed the steps of thematic synthesis described by Thomas and Harden [47]. First, line-by-line coding was undertaken of the findings or results of each paper. The results section of each paper was read and re-read, with codes noted in the margin before being transferred into a separate word document. This process enabled the translation of concepts between studies, as the list of codes was continuously being added to, with new codes developed as needed. Coding took place at a semantic rather than a latent level, to reflect the variety of methods of qualitative analysis had been used in the studies. An inductive approach was taken, as analysis was led by the data rather than a predetermined framework or theoretical model [54].

The second step involved grouping clusters of codes together to form descriptive themes, through examining the similarities and differences between codes. At this stage a synthesis which was reflective of the findings of the included studies was developed. The final stage of the analysis involved going beyond these findings and creating analytical themes that answered the research question and focussed on understanding what the key functions of online peer support were for the caregivers. This process was iterative and involved going backwards and forwards between the descriptive themes and potential abstract, analytical themes until final overarching themes which captured the sense of the underlying data whilst answering the research question were decided upon.

It was recognised that the generation of the analytical themes is a subjective process impacted by the researcher’s individual personal experiences, views and context. Consequently, I reflected on the personal influences considered likely to impact the synthesis prior to starting the analysis and revisited this regularly during supervision. I identified that my own use of health-related forums may have directed my focus towards aspects of participants’ experiences in the included studies which resonated with my own. Recognition of this helped to maintain balance of focus. My reflections highlighted that working with caregivers of people with mental and physical health conditions across settings in the NHS during clinical psychology training provided me with insight into the distress which can accompany caring for someone with a chronic health condition. This insight, together with previous research experience of online interventions for caregivers, shaped the aim of the review and underpinned the objective of contributing clinically relevant generalisable findings to the knowledge base.

3. Results

3.1 Study characteristics

Table 1 shows a summary of the 34 included studies. The studies were published between 2001 and 2019 and were conducted in the USA [39, 55-72]; the UK [35, 73-76]; Sweden [77-81]; South Africa [33]; Canada [82, 83]; Norway [84] and Malaysia [85]. The studies focussed on a range of physical and mental health conditions including Alzheimer’s disease, cancer, post-traumatic stress disorder, diabetes and schizophrenia. Eighteen of the studies analysed data representing the content of online peer support platforms which were accessible to the public, [39, 56-58, 62-65, 67, 68, 70, 72-75, 81, 82, 85] and the remainder of the studies analysed data which were research generated.

[INSERT TABLE 1]

3.2 Quality appraisal

CASP scores for the studies ranged from 19/30 to 27/30 and Reliability and Usefulness scores ranged from 2/6 to 6/6 indicating varied quality. The quality appraisal scores were used to guide the order the studies were prioritised, with higher scoring studies read before those with lower scores [86]. However, none of the studies were excluded on the basis of quality, as the subjective nature of this assessment has been highlighted [87, 88]. In addition, although some studies may have had lower levels of quality it was considered important not to overlook their potential for making a significant contribution to the synthesis. Consequently, it was decided that all available data should be included with relative contributions to the themes noted. Table 2 shows the quality appraisal scores for each study.

[INSERT TABLE 2]

3.3 Thematic synthesis

Two overarching analytical themes were developed: (i) meeting caregivers' needs for a new type of sustaining friendship, and (ii) creating a space to express uncomfortable emotions. Both themes capture key elements of caregivers' use and experience of online peer support and contain subthemes which provide the detail which underpins their development. Table 3 shows the themes and subthemes.

[INSERT TABLE 3]

Consistent with Thomas and Harden's method of thematic synthesis [47] , the subthemes represent concepts or domains identified in the findings of the included studies, whereas the overarching themes have been generated by analysing patterns of meaning across the studies in response to the research question. The contribution of each study to the themes and subthemes is shown in Table 4. This illustrates that the themes and subthemes have been developed from the findings across the included studies.

The findings of 33 of the 34 studies contributed to both overarching themes, with 20 studies contributing to 4 or more of the 6 individual subthemes. The studies which made relatively small contributions to the themes had mixed method designs which provided less qualitative material to synthesise [69, 80] or focussed on particular research questions such as the information needs of PTSD caregivers [67] or self-help strategies used by Alzheimer's caregivers [72].

A pattern was observed in the development of the themes as 16 of the 20 studies which contributed to 4 or more subthemes analysed caregivers' postings on online support forums or message boards. This category of study scored highly on the Reliability and Usability quality appraisal, particularly as the findings privileged the voice of the participants and provided a depth of analysis which moved beyond the descriptive. For example, two studies [56, 61] contributed to 5 and 6 subthemes respectively and both scored a maximum of 6 on the Reliability and Usefulness appraisal criteria. However, a high level of contribution and high Reliability and Usefulness score did not necessarily accompany a high CASP score. In such studies [58, 73] scores were negatively impacted as the relationship between participant and researcher had not been considered, which is perhaps due to the nature of the public data and lack of participant contact. CASP scores were also affected when ethical issues surrounding the use of public data were not fully addressed. Studies which scored low on both quality appraisal measures and made low contributions to the themes lacked in-depth qualitative data analysis due to mixed-methods designs [69, 80]; less detailed deductive content analysis [70]; and focused on the development of the peer support intervention [55].

[INSERT TABLE 4]

3.3.1 Theme 1: Meeting caregivers' needs for a new type of sustaining friendship

This theme captures the sense that new caregivers have an acute need for interaction with peers who understand the specific demands of caring for someone with a physical or mental health condition, and with whom they can share information and advice, and mutual emotional support. This need has arisen due to the impact of the caregiving role and often cannot be met through existing relationships, due to a lack of shared experience or a reluctance on the part of caregivers to share details with their immediate social circle due to stigma. Caregivers' engagement with online peer support is often characterised by the formation of interactive relationships over time which have the qualities of a sustaining friendship. This sense of friendship emerges from a place of isolation, which is mitigated through connections formed online. The subthemes combine to illustrate how caregivers' needs for this type of friendship are expressed and met through online peer support.

Exchange of advice and information: The interaction between caregivers online has a reciprocal quality as advice is given and received. This pattern resonates with the idea of a mutually beneficial friendship captured by the overarching theme.

Caregivers appreciate the advice and information they receive from peers in response to requests on a wide range of subjects. *"Comfort of knowing that I can get accurate information from people who are going through the same thing"* [55], p.508. The included studies highlight that information is sought and provided about very specific difficulties which relate to the health condition. Advice often features clear strategies to manage problems which have been used successfully by other caregivers. This emphasises that shared experience is a key element in interactions between caregivers online.

"I've gotten some really, really good information from other people. I've gained a lot just from reading information that others have shared." [69], p.258.

"Always tell them what is going on around them and what is happening next. And in every situation try to see it from their perspective in order to understand their needs better." [57], p.28, (Dementia).

"Coke works wonders for [my son] when he gets spinal headaches!" [62], p.1235, (Cancer).

"If a child wants something, they should try and use the word for the item as well as using the correct picture, such as 'fridge.'" [33], p.3468, (Autism).

"The nurse told me that my wife's dementia is rapidly worsening. From week to week, I notice major changes. One problem is, what do I tell her? What have you that have been in the same situation told your spouses?" [84], p.5, (Dementia).

One study raised the issue of the accuracy of information provided by peers and analysed incidences of medical misinformation in online postings [64]. Incidences of misinformation were found to be rare, with caregivers' non-professional status highlighted in blog posts.

"If you see some technique here that you would like to try, call your doctor, use common sense, and remember: I am not a doctor ... I'm just a mother of three boys with type 1 diabetes. That is it. Mother. Not doctor. Blogger. Not doctor. Friend. Not doctor." [64], p.5.

Caregivers discussed the benefit they derive from providing guidance to peers. Being able to help others can make sense of struggles experienced, as something positive can emerge from difficult times. In this way, meaning and value are ascribed to negative experiences.

"I have felt that my experiences are worth something, that I am not only an old lady in my seventies who should just sit and be quiet." [78], p.2316.

"I guess we all have no choice but to keep going day to day, keep writing our blogs and our books and hoping that the hardships we've experienced aren't for nothing, that maybe by telling them, someone else will be helped." [56], p.43.

Instilling hope and support: Messages of hope were prevalent, with the aim of instilling motivation and optimism in peers who indicate that they are struggling. The cyclical nature of caregiving is acknowledged, with experiences of fluctuating between bad and good times described. This underpins reciprocal interactions where caregivers who are feeling more positive, sustain and foster hope in those who are overwhelmed with difficulties. Those who receive help often provide it to others in similar situations when they feel able. *"These are the folks who hold the light for me so that I can see my way to a bit of peace; sometimes I hold the light for them."* [56], p.41. The nature of these interactions supports the concept of a friendship, or an enduring relationship which is sustained over time.

"But we are not the only ones that are going through this kind of struggle and we make it." [60], p.27.

"Life has many twists and turns and not all are easy and not all are pleasant but to have walked the walk you are now walking puts you in a class by yourselves. You have learned love and compassion and patience and understanding and strength and endurance and the list goes on." [61], p. 634.

*"Don't give up! You become stronger than you think from this shit. No matter how f***ing bad it hurts, how weak you feel, you shouldn't give up. Keep on fighting, I've done it and believe me, it will get better even if it sometimes feels hopeless.''* [81], p.1604.

However, some of the studies indicate that some caregivers have a contrasting experience when reading peers' accounts. Descriptions of negative situations can diminish optimism and positivity and are cited as reasons for disengaging with online peer support.

"The drawback, you always end up with one or two that are negative Nellys, the negative ones that don't have anything positive going on in their life...You're going to have your ones that just won't ever be happy. Because they're not happy, they don't want anybody else to be happy." [69], p.9.

There when you need them: The flexibility of online peer support is highlighted by participants in that it is accessible when needed. This contributes to the overarching theme of a sustaining friendship as it reflects the consistency and dependability of a strong relationship that can be called upon when needed. This is particularly relevant to caregivers whose daily schedules are overloaded due to their caregiving responsibilities.

"I used it when other support was closed during late evenings, weekends and at night-time when I couldn't sleep. It was often when other support was unavailable." [77], p.492.

"With online support you can sign on at 2.00 in the morning and get comfort from just typing out your story. It might be the only time you have." [59], p53.

However, caregivers highlighted frustrations when their requests for information went unanswered, and it is observed that online peer support needs to be sufficiently populated in order to function effectively.

"I have to say that I am a bit disappointed. I know that I am not the only parent with a child suffering. I am also finding it hard. Please, if any other parent could help please get in touch." [73], p.874.

"So I think one must always accept that in such contexts, there are people that are logged in very often, that are very active, and that there are others who are not there so often and who are not so active." [80], p. 379.

3.3.2 Theme 2: Creating a space to express uncomfortable emotions

Caregivers generally consider online peer support to be a non-judgemental environment to express thoughts and feelings which would be difficult to share in existing social networks. The subthemes describe the benefits derived from having a space to express emotions and the nature of difficult feelings expressed about the caregiving relationship and the impact of caring on roles and personal identity. The emotions expressed online by caregivers with their peers reflect feelings which contrast with ideas of typical family structures or caring relationships, which could underpin caregivers need to find an outlet for their thoughts.

The benefits of expressing emotions: Caregivers describe the cathartic benefits of expressing and describing their emotions to other caregivers who have experienced similar feelings. The physical and emotional relief felt by caregivers is palpable, as they highlight how connecting with peers allows them to "*share and let off steam*" ([35] p.9), and *"get things off your chest"* ([77], p.491*)*. The need to express emotions is normalised as caregivers empathise with their peers, "*it's OK to have a cry spell every once in a while, it's what keeps us sane."* ([62], p.1237).

"I seriously feel a little better after lodging my complaint with the complaint department (aka my online caregiving friends). You guys understand and don't judge when bad days are had." [56], p.41.

"Please do not blame yourself, we have all felt if only. I have done the same as you, please do not beat yourself up." [73], p.874.

The idea that online peer support offers a ring-fenced space to express emotions is suggested by caregivers who indicate that they would not feel comfortable sharing their feelings elsewhere for fear of negative judgment. Caregivers are also keen to protect the person they are caring for from their emotions. The anonymity of the online format supports expression of emotions and develops the concept of a non-judgemental environment.

"Sorry, I just wanted to use this platform to vent my feelings and I don't want to be thought of as self- pitying and self-centre." [75], p.281.

The process of writing online is insightful and helps caregivers to see more clearly what is happening to them, with the benefits of anonymity. This contrasts with the immediacy of face-to-face communication.

"I think friend sourcing has been really helpful because I can actually evaluate my feelings and understand what she needs from me, and I don't portray any of my feelings onto her, you know?" [71], p.118.

"I don't mind meeting other people face-to-face, but at the same time, it's easier to express your feelings on the web where you can be more anonymous. Sometimes it's easier to write how you're feeling." [72], p.493.

The caregiving relationship: Caregivers express their emotions about their relationship with the person they are caring for, which indicates the difficulties and strain associated with the caring role. Sharing similar experiences with peers means that caregivers feel their accounts are met with understanding and are of value to other caregivers in indicating empathy and compassion. Caregivers have often lost the relationship with the person they felt closest to due to their health condition, and value the opportunity to share the loneliness, grief, anger and frustration of this with other caregivers online. The anonymous format of online peer support may facilitate the ability to be honesty about these emotions, without the social constraints of being a "good caregiver".

"I tend to feel all the emotions so close together and think they often get mixed up. One minute I am mad because I am being used like a servant then the next I am happy to be relied on." [40], p.39.

''Then, when mum came home after having been in psychiatric care for 2 months, I could hardly look at her, I couldn't forgive her. I stopped going to school, I hated everything, stopped playing soccer." [81], p.1603.

"My wife has always been a very upbeat, personable person, with a great humour. She rarely smiles now and isn't into conversation…it makes me feel so lonely." [40], p.39.

"I do sympathise; I know exactly how you feel - I think one of the hardest times for me was when I realised that you can't share your worries or problems with your parents anymore. They are no longer there for you." [75], p.280.

Renegotiation of identity: Caregivers use online peer support to discuss changes in their own personal identity brought on by the caregiving role. This is apparent in spousal relationships, where the transition from wife or husband to caregiver is characterised by loss and previous roles are changed. Similarly, children of parents with mental health difficulties describe the reversal of traditional roles. Parents of children with cancer and with autism discuss feelings of sadness that their children will not meet developmental milestones. Caregivers feel able to discuss difficult and taboo feelings with regards to identity due to the shared experiences in the peer group, which suggests that online peer support provides a safe space to discuss topics which are not voiced in caregivers' external social networks.

''After 2 weeks she was sent home, even though she didn't feel ready. I and my sister had to move home and take care of her ourselves. I will NEVER forgive the psychiatric institution for what they did to me and my sister. We literally had to act like 'extra mothers' to our own mother." [81], p.1605.

"I thought that once I raised my children, I would be able to enjoy some quiet time, a weekend away from work and family, a chance to take golf lessons or even go out with friends without having to make sure my father eats, takes his medicine and can get himself ready for bed on his own." [61], p. 633.

"This is not a role I chose but found myself in when my daughter faced this devastating illness. What shocked me was how abruptly I changed parenting styles." [82], p.393.

4. Discussion and conclusion

4.1 Discussion

This review synthesised qualitative findings on the function of online peer support for caregivers and resulted in two themes; “Meeting the need for a new type of sustaining friendship”, and “Creating a space to express uncomfortable emotions.”

Caregivers used online peer support as it met the need for a new type of supportive interaction precipitated by the impact of caring (Theme 1). Caregivers highlighted that it was difficult to meet this need through existing social networks due to a lack of shared experience [58, 62, 78]. Specific information and advice about the health condition of the person being cared for was exchanged in a reciprocal way between caregivers. This is consistent with research indicating that identification with others is a key communication mechanism which mediates social support in online support groups [89]. The caring role resulted in a requirement for engagement and identification with a new group of peers which resonates with social identity theory [90, 91]. Social identity theory focusses on group membership and self-identity and highlights that being a member of a group is an important component of a person’s sense of self. Participants formed connections with peers online and became members of new groups, reporting positive consequences.

The importance of reciprocal interactions online was described by participants, with caregivers appreciating that their requests for information were responded to. The negative impact when this did not happen was highlighted [73], which further emphasises the need for a sustained flow of communication when engaging with peers online. This also suggests that online peer support needs to be sufficiently populated to support interactions between caregivers. Whilst this issue has been raised in implementation research [92, 93] it was not an area of focus for the studies in this review.

Participants appreciated that advice was based on real experiences described by peers which made it more accessible and credible [55, 76]. This is consistent with research which emphasises the need for input from service users and caregivers in online intervention design [94-96]. However, the issue of the accuracy of information provided by peers was raised, with one study in this review analysing incidences of medical misinformation in online postings [64]. Whilst very few examples of misinformation were found, accuracy of information is highlighted as a factor for consideration when considering online peer support for caregivers. Nine studies featured moderated forums where content was overseen, which enabled inappropriate postings to be removed.

Caregivers were uplifted by positive messages of hope and support from peers who had overcome problems and transitioned from a position of isolation to feeling part of a new community [35, 60, 67]. Caregivers appreciated the flexibility of the online format and the opportunity to connect with peers without the limitations of geography or time [56]. Research emphasises this advantage of online support groups, and highlights that it is particularly relevant to carers whose schedules are constrained by their caring responsibilities [25, 42, 97]. The potential for support to be delivered online has been recognised by the NHS, with the development of online interventions endorsed [32].

Caregivers used online peer support to express emotions which could be uncomfortable to voice in their existing social networks (Theme 2). Discussions involving negative or confused feelings about the person being cared for, and caregiver identity were prevalent [40, 64]. This is consistent with research highlighting that problems and disagreements are common in the caregiving relationship, with conflicts surrounding the nature of care needs [98], knowledge about the condition [99] and risk [100]. Caregiving also disrupts social and cultural norms regarding family structures including situations where children take on the role of parents and spouses become caregivers [101, 102]. However, whilst roles within the family are impacted by caring, social constructions connected with the female caregiving identity appear to be maintained as females fulfil the majority of caregiving tasks [103]. Expressing negative emotions about caregiving and the person being cared for can be uncomfortable for caregivers as this transgresses societal and cultural norms about ideal caring.

Women seem to experience more distress from caregiver burden than men and high levels of distress are associated with feelings of incompetence and insecurity about caregiving [104]. It is notable that most of the participants in this review were female and that expressions of distress and burden were often accompanied by descriptions of guilt. Insecurity about caregiving ability could also underpin Theme 1, which captures participants' expressions of need for information and advice as well as reassurance about the performance of their role.

Caregivers tend to conceal their caregiving activities and the distress associated with it from the person being cared for and with others in everyday life [105, 106]. It is suggested that this concealment could be due to a desire to overstate the independence of the person being cared for at the expense of positive caregiver identity [107]. Perceived stigma about the underlying condition could also be a factor impacting caregiver identity, as this has been highlighted in relation to asthma [108], acquired brain injury [26], and mental health conditions [109, 110]. This resonates with the findings of this review in that participants described isolation in the caring role and expressed a need for social support from peers who had experienced similar situations and emotions.

4.2 Strengths and limitations

A strength of this review is the identification of the ways in which caregivers engage with peers online which apply across a range of physical and mental health conditions and to a variety of caring relationships. The overarching themes were developed from the findings of studies which analysed both public websites and interview data where participants described their experiences. This variety of data sources gives strength to the patterns of meaning which were developed into the analytical themes.

The quality appraisal process was illuminating as findings based on public data tended to score more highly on reliability and usefulness criteria and made a more significant contribution to the development of the themes. It was noticeable that these studies privileged the voice of the participants and analysis was grounded in the data. However, a lack of discussion about the ethical implications of using public data and consideration of reflexivity led to lower CASP appraisal scores in some cases. Whilst these studies analysed communication between caregivers which was not impacted by researchers, they only featured caregivers who were actively engaged with online peer support. This fails to include the experiences of those who decided not to contribute or remain engaged and the reasons behind this. Studies which analysed interview and focus groups captured more of the disadvantages of online peer support, but the overall synthesis resulted in an illustration of the benefits. Exploring the reasons that caregivers disengage from online peer support merits further investigation, as understanding this is important in evaluating its function as a source of support and information. The included studies do not cover passive users of online peer support, and it has been highlighted that benefits can also be derived from visiting a website in order to “lurk” rather than actively communicate [111, 112].

The comprehensive nature of the search criteria resulted in a large number of studies to screen featuring a variety of research designs and data sources. The search could have been made even more exhaustive by adding forward citation searching to the process. The screening of papers was conducted independently, and this may have benefited from the input of a second screener to validate inclusion decisions. Similarly, collaboration on the quality appraisal process could have countered subjectivity.

4.3 Conclusion

This review synthesised a broad range of studies and developed themes which reflect the function of online peer support for caregivers. The findings illuminate caregivers' need for flexible, emotionally supportive and reciprocal interaction which resonates with the concept of a sustaining friendship based on experiential similarity. Online peer support provides a safe space to express emotions away from the caregiving relationship. These factors are common to a range of mental and physical health conditions and caring relationships. The findings expand knowledge of the need for and provision of caregiver support, and highlights areas meriting further research. This will hopefully inform the development of resources for caregivers which benefit from the potential offered by online platforms.

4.4 Practice implications

This review indicates that caregivers derive benefit from connecting online with peers in terms of social support, emotional support and the exchange of information which helps them in their caregiving role. Common experience and identity underpin this. This has implications as service user informed peer support forums have the potential to meet caregivers' needs for support and mitigate the psychological and physical impact of caregiver burden. An online format is inexpensive when compared to face to face professional support and flexible for users. However, operationalising online peer support is less clear. Whilst this review showed that both public websites and clinically endorsed formats were appreciated by participants, there was a lack of detail on how communication was established, forums became populated and interaction sustained. The role of a moderator in prompting discussions, monitoring the exchange of clinical information, managing risk, and curtailing anti-social behaviour also requires further investigation.

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Figure 1 - Systematic search process

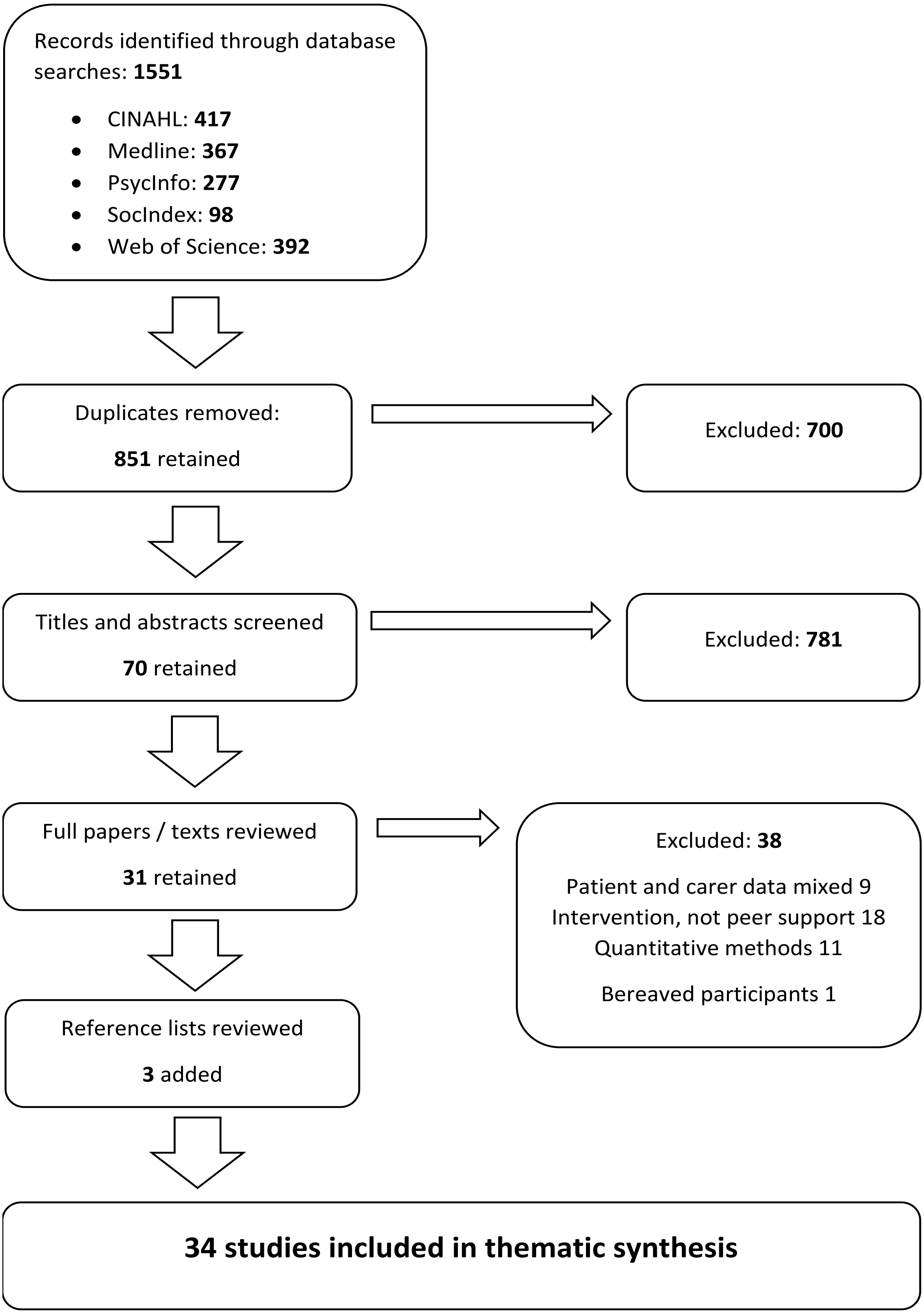

Table 1: Table of included studies

Author and Year	Country	Research Aims	Number of Participants	Relationship to Care Recipient	Condition	Data Collection	Methodology
1. Akre, Polvinen, Ullrich & Rich, (2018) [55]	USA	To explore caregivers' experiences of using a secure social media forum	46	Parent	Neuro fibromatosis	Interviews (within a mixed methods study)	Thematic analysis
2. Andersson, Erlingsson, Magnusson & Hanson, (2017) [77]	Sweden	To describe working carers' experiences of having access to a web-based family carer support network	9 (female)	Child (7), spouse (1), in law (3), niece (1) (note: multiple family members cared for)	Dementia (6), neurological disease (1), stroke (1), chronic pain (1), comorbidities (2), frailty (1)	Interviews	Thematic analysis
3. Anderson, Hundt, Dean, Keim-Malpass, & Lopez, (2017) [56]	USA	To explore how caregivers use blogs as part of the individual caregiving experience	9 (8 female, 1 male)	Child (7), spouse (2)	Dementia	Transcripts of blog posts	Thematic content analysis
4. Anderson, Hunt, Dean & Rose (2019) [57]	USA	To identify themes associated with self-care strategies practiced by family caregivers of people with dementia	9 (8 female, 1 male)	Child (7), spouse (2)	Dementia	Transcript of blog posts	Thematic content analysis
5. Anderson, Hundt, & Rose, (2019) [72]	USA	To examine the non-pharmacological strategies used by caregivers of people with dementia as expressed in caregiver blogs	9	Child (7), spouse (2)	Dementia	Transcripts of blog posts	Thematic content analysis

6.	Andreasson, Andreasson, & Hanson, (2018) [78]	Sweden	To describe how older carers conceptualise and understand their identity as carers on an online social forum	44 (34 female, 10 men, mean age 64.7 years)	Spouse (30), parent (11), other relative (3)	Dementia	Postings on a closed forum	Thematic content analysis
7.	Bloom, Beck, Wen-Ying, Reblin, & Ellington, (2019) [58]	USA	To explore caregivers' writings about their experiences of caring for an adult with cancer on a social media health communication website	37	Child (14), spouse (10), friend (3), sibling (2), unknown (8)	Cancer	Postings on a social media website	Thematic content analysis
8.	Cole, Kharwa, Khumalo, Reinke, & Karrim, (2017) [33]	South Africa	To explore caregivers' use of a social media support group on WhatsApp	6 (5 female, 1 male, 23-48 years)	Parents	Autism	Interviews	Thematic analysis
9.	Colvin, Chenoweth, Bold, & Harding, (2004) [59]	USA & Canada	To explore the unique advantages and disadvantages of online social support identified by caregivers	63 (female, 56; males, 7)	Wife (29), husband (6), partner (1), daughter (19), son (1), daughter in law (2), granddaughter (2), other (3)	Mental and physical health conditions, (50% Alzheimer's disease)	Thematic analysis of responses to open ended questions in a web-based study	Thematic analysis
10.	Coulson & Greenwood, (2012) [73]	UK	To explore the role of online support groups in supporting families affected by childhood cancer	181	Family members	Cancer	Conversation threads from 3 public discussion boards	Thematic content analysis
11.	Diefenbeck, Klemm, &	USA	To explore therapeutic factors emerging in a peer-led, asynchronous, online support	11 (10 female, 1 male)	Spouse (3), daughter (4), mother (2), son (1),	Physical and mental health conditions	Postings to an online support group	Qualitative content analysis

	Hayes, (2014) [60]				granddaughter, (1)			
12.	Diefenbeck, Klemm, & Hayes, (2017) [61]	USA	To examine content themes emerging from a non-facilitated, peer-only, unstructured, asynchronous online support group for caregivers	16 (female 40+ years old)	Spouse (4), daughter (7), mother (3), daughter in law (1), granddaughter (1)	Mental and physical health conditions	Messages posted to an online support group	Thematic content analysis
13.	Gage-Bouchard, LaValley, Mollica, & Beaupin, (2017) [62]	USA	To examine the nature of support exchanges between parents of pediatric cancer patients as they happen in real-time, naturally occurring interactions on Facebook	Not specified	Parent	Cancer	18 Facebook pages	Inductive Thematic analysis
14.	Huws, Jones & Ingledew, (2001) [74]	UK	To illuminate the functions of an email group used by parents of children with autism	Not specified	Parents	Autism	Messages posted to an email discussion list	Grounded theory
15.	Klemm, & Wheeler, (2005) [39]	USA	To identify themes embedded in online messages posted by members of an online support group	38 (female)	Wife (27), daughter (8), sister (2), mother (1)		Messages posted to an online support group	Thematic content analysis
16.	Kruk, (2015) [75]	UK	To investigate how online support groups allow Alzheimer’s carers to negotiate disruptive aspects of identity	Not specified	Not specified	Alzheimer’s disease	Forum discussion threads	Thematic analysis
17.	LaMarre, Robson, & Dawczyk, (2015) [82]		To explore how parents engaged in family-based therapy might use blogs to meet their support needs	5 (female)	Mothers	Eating disorders	Blog posts	Thematic content analysis

18. Lichenstein, McDonough, & Matura, (2013) [63]	USA	To gain an understanding of how caregivers of people with pulmonary hypertension are using an online discussion board	98	Mother (46), father (3), wife (11), husband (14), daughter (2), son (1), parent (12,) partner (2), stepfather (1), sibling (2), offspring (5)	Pulmonary hypertension	Discussion board posts	Thematic analysis
19. Male, Fergus, & Stephen, (2015) [40]	Canada	To examine participant-generated discourse taking place within four synchronous, professionally facilitated online support groups	25 (19 female, 6 male, 27-75 years)	Spouse or partner (19), parent (5), child (1)	Cancer	Transcribed transcripts of an online chat group	Thematic analysis
20. McKechnie, Barker, & Stott, (2014) [35]	UK	To explore experiences of being on an online forum and possible positive and negative outcomes	8	Not specified	Dementia	Interviews as part of a mixed methods study	Inductive thematic analysis of interviews
21. Mohd Roffeei, Abdullah, & Basar, (2015) [85]	Malaysia	To examine the types of social support messages exchanged between parents and/or caregivers of children with Autism Spectrum Disorders	Not specified	Parents and other caregivers	Autism	Posts from autism support groups	Thematic content analysis
22. Oser, Oser, McGinley, & Stuckey, (2017) [64]	USA	To better understand the issues faced by caregivers to children with Type 1 diabetes	3	Mothers (2), father (1)	Diabetes	Blog posts	Thematic analysis
23. Perron. (2002) [65]	USA	To explore the patterns of content which emerge within the messages of an online forum	33 (26 female, 6 male)	Family members	Schizophrenia and related mental health conditions	Messages posted to an online forum	Discourse analysis

24.	Reinke & Solheim, (2015) [66]	USA	To explore how parents experience emotional, informational and social support in the online environment	14 (female)	Mothers	Autism	Interviews	Interpretative Phenomenological Analysis
25.	Russin, & Ferrell, (2019) [67]	USA	To analyse questions on an online discussion forum to better understand the information needs of caregivers.	195	Friends, family members, significant others	PTSD	Forum posts	Thematic analysis
26.	Sillence, Hardy, Briggs, & Harris, (2016) [76]	UK	To explore how carers engage with online peer accounts and how the relate these accounts to their own caring experiences	20	Partner or spouse (19), parent (1)	Multiple sclerosis	Focus groups and interviews	Thematic analysis
27.	Solli, Bjørk, Hvalvik, & Hellesø, (2018) [84]	Norway	To explore the relationships that emerge amongst caregivers of persons with dementia and stroke in a closed online support group	40 (20 female, 20 male, 42-49 years)	Not specified	Dementia and stroke	Forum messages	Thematic analysis
28.	Stjernswärd, & Hansson, (2014) [79]	Sweden	To explore relatives’ situations in an online forum, together with the kind of social support exchanged	10 (9 female, 1 male, mean age 60.5 years)	Child (3), parent (3), partner (3), other (1)	Depression	Forum posts (mixed methods study)	Thematic content analysis
29.	Stjernswärd & Ostman, (2010) [80]	Sweden	To explore user experience of a website for relatives of people with depression	16 (female)	Partner (8), parent (5), children (3)	Depression	Forum posts and interviews	Thematic content analysis
30.	Sullivan, (2008) [68]	USA	To understand the everyday lives of those caring for one or more children with chronic asthma	Not specified	Mothers	Asthma	Online support group messages	Thematic analysis
31.	Vaughan, Trail, Mahmud, Dellva, Tanielian, &	USA	To examine perceptions of a web-based social support intervention for informal caregivers of wounded, ill, and injured United States military service members and veterans	15	Not specified	Wounded military veterans	Focus groups and interviews	Thematic content analysis

	Friedman, (2018) [69]							
32.	White & Dorman, (2002) [70]	USA	To explore recurring themes, subjects and patterns of messages on an online message board	Not specified	Not specified	Alzheimer’s disease	Online message board posts	Thematic content analysis
33.	Widemalm, & Hjärthag, (2015) [81]	Sweden	To investigate what offspring of parents suffering from mental illness communicate about on open internet forums	197 (13-49 years)	Children	Mental health conditions	Forum discussion threads	Thematic analysis
34.	Wilkerson, Brady, Yi, & Bateman. (2018) [71]	USA	To explore caregivers’ experiences of using a peer support forum within an intervention	12	Not specified	Alzheimer’s disease	Interviews (within mixed methods study)	Thematic analysis

Table 2: Quality appraisal scores for each study, (CASP [52]; Reliability and Usefulness [50])

Author and year	**CASP** (each question scored out of 3)											**Reliability and Usefulness** (1 = low weighting; 2 = medium weighting; 3 = high weighting)		
	1. Clear aims of research?	2. Qualitative Methodology Appropriate?	3. Research Design appropriate to address aims?	4. Recruitment Strategy Appropriate?	5. Data Collected in a way that addressed research issue?	6. Relationship between researcher and participants considered	7. Ethical issues taken into consideration?	8. Data Analysis Sufficiently Rigorous?	9. Clear Statement of findings?	10. How Valuable is the Research?	**Total**	**Reliability and trustworthiness of the findings** Were steps taken to increase rigour in the sampling / data collection / data analysis? Were the findings were grounded in the data?	**Overall usefulness of the findings** Consider the findings in terms of breadth (description) and depth (analysis). To what extent are the perspectives and experiences of carers privileged?	**Total**
1. Akre, Polvinen, Ullrich & Rich, (2018) [55]	3	3	2	2	2	1	1	2	2	3	**21**	1	1	**2**
2. Andersson, Erlingsson, Magnusson & Hanson (2017) [77]	3	3	3	2	3	2	1	2	3	2	**24**	2	1	**3**
3. Anderson, Hundt, Dean, Keim-Malpass,	3	3	3	3	3	1	3	2	3	3	**27**	3	3	**6**

	& Lopez (2017) [56]														
4.	Anderson, Hundt, Dean & Rose, (2019) [57]	3	3	3	2	3	1	2	2	3	3	**25**	2	1	**3**
5.	Anderson, Hundt & Rose, (2019) [72]	3	3	3	2	3	1	3	3	3	2	**26**	2	1	**3**
6.	Andreasson, Andreasson, & Hanson, (2018) [78]	3	3	3	3	3	1	2	3	3	3	**27**	2	2	**4**
7.	Bloom, Beck, Wen-Ying, Reblin, & Ellington, (2019) [58]	3	3	3	2	3	1	1	3	3	3	**25**	2	3	**5**
8.	Cole, Kharwa, Khumalo, Reinke, & Karrim, (2017) [33]	3	3	3	2	3	1	2	2	3	3	**25**	2	2	**4**
9.	Colvin, Chenoweth, Bold, & Harding, (2004) [59]	3	3	3	2	2	2	1	3	3	2	**24**	1	2	**3**
10.	Coulson & Greenwood, (2012) [73]	3	3	3	2	2	1	1	2	3	2	**22**	2	3	**5**
11.	Diefenbeck, Klemm, & Hayes, (2014) [60]	3	3	3	3	2	1	2	2	2	3	**24**	3	3	**6**
12.	Diefenbeck, Klemm, & Hayes. (2017) [61]	3	3	3	2	2	2	1	2	3	2	**23**	3	2	**5**

13. Gage-Bouchard, LaValley, Mollica, & Beaupin, (2017) [62]	3	3	3	3	3	1	1	3	3	3	**26**	2	2	**4**
14. Huws, Jones & Ingledew, (2001) [74]	3	3	2	2	3	2	3	2	3	2	**25**	2	2	**4**
15. Klemm & Wheeler, (2005) [39]	3	3	3	2	2	1	2	1	2	3	**22**	2	3	**5**
16. Kruk, (2015) [75]	3	3	2	2	2	2	3	2	2	2	**23**	2	2	**4**
17. LaMarre, Robson, & Dawczyk. (2015) [82]	3	3	2	1	1	1	2	2	2	2	**19**	2	2	**4**
18. Lichenstein, McDonough, & Matura, (2013) [63]	3	3	2	2	2	1	1	2	3	2	**21**	2	2	**4**
19. Male, Fergus, & Stephen, (2015) [40]	3	3	3	2	2	1	2	2	3	2	**23**	2	3	**5**
20. McKechnie, Barker, & Stott, (2014) [35]	3	3	3	3	2	3	1	2	3	3	**26**	2	1	**3**
21. Mohd Roffeei, Abdullah, & Basar (2015) [85]	3	3	3	3	2	2	1	2	3	2	**24**	2	1	**3**
22. Oser, Oser, McGinley, & Stuckey, (2017) [64]	3	3	3	3	2	2	1	2	3	3	**25**	2	3	**5**
23. Perron, (2002) [65]	3	3	3	2	2	1	2	2	2	2	**22**	1	2	**3**

24. Reinke & Solheim, (2015) [66]	3	3	3	2	3	2	1	3	3	3	**26**	3	2	**5**
25. Russin, & Ferrell, (2019) [67]	3	3	3	3	3	1	3	2	3	3	**27**	2	2	**4**
26. Sillence, Hardy, Briggs, & Harris, (2016) [76]	3	3	3	3	2	1	2	1	2	2	**22**	2	1	**3**
27. Solli, Bjørk, Hvalvik, & Hellesø, (2018) [84]	3	3	2	2	3	1	2	2	2	2	**22**	2	3	**5**
28. Stjernswärd, & Hansson, (2014) [79]	3	3	2	3	2	1	1	2	2	3	**22**	1	2	**3**
29. Stjernswärd & Ostman, (2010) [80]	3	3	2	2	2	1	2	2	2	2	**21**	1	2	**3**
30. Sullivan, (2008) [68]	3	3	3	2	2	2	1	2	3	3	**24**	2	3	**5**
31. Vaughan, Trail, Mahmud, Dellva, Tanielian, & Friedman, (2018) [69]	3	3	3	2	2	1	1	2	2	2	**21**	1	1	**2**
32. White & Dorman, (2002) [70]	3	3	2	2	2	1	1	1	2	2	**19**	1	1	**2**
33. Widemalm, & Hjärthag, (2015) [81]	3	3	3	2	3	1	2	3	3	2	**25**	2	3	**5**
34. Wilkerson, Brady, Yi, & Bateman, (2018) [71]	3	3	2	3	2	1	1	2	2	2	**21**	2	2	**4**

Table 3: Themes and subthemes

Theme 1: Meeting caregivers’ needs for a new type of sustaining friendship	Theme 2: Creating a space to express difficult emotions
Exchanging information and advice	The benefits of expressing emotions
Instilling hope and support	The caring relationship
There when you need them	Renegotiation of identity

Table 4: Contribution of each study to themes

Author and year	Meeting caregivers’ needs for a new type of sustaining friendship			Creating a space to express difficult emotions		
	Exchange of advice and information	**Instilling hope and support**	**There when you need them**	**The benefits of expressing emotions**	**The caregiving relationship**	**Renegotiation of identity**
1. Akre, Polvinen, Ullrich & Rich, (2018) [55]	✓				✓	
2. Andersson, Erlingsson, Magnusson & Hanson (2017) [77]		✓	✓		✓	
3. Anderson, Hundt, Dean, Keim-Malpass, & Lopez (2017) [56]	✓	✓	✓	✓	✓	
4. Anderson, Hunt, Dean & Rose (2019) [57]		✓			✓	
5. Anderson, Hundt & Rose, (2019) [72]	✓	✓		✓		
6. Andreasson, Andreasson, & Hanson, (2018) [78]	✓				✓	✓
7. Bloom, Beck, Wen-Ying, Reblin, & Ellington, (2019) [58]	✓	✓		✓	✓	

8.	Cole, Kharwa, Khumalo, Reinke, & Karrim, (2017) [33]		✓	✓		✓	
9.	Colvin, Chenoweth, Bold, & Harding, (2004) [59]	✓	✓			✓	✓
10.	Coulson & Greenwood, (2012) [73]	✓	✓		✓	✓	
11.	Diefenbeck, Klemm, & Hayes, (2014) [60]	✓	✓	✓	✓	✓	✓
12.	Diefenbeck, Klemm, & Hayes, (2017) [61]	✓	✓	✓	✓	✓	✓
13.	Gage-Bouchard, LaValley, Mollica, & Beaupin, (2017) [62]	✓	✓			✓	
14.	Huws, Jones & Ingledew, (2001) [74]	✓	✓	✓		✓	
15.	Klemm, & Wheeler, (2005) [39]	✓	✓		✓	✓	
16.	Kruk, (2015) [75]	✓			✓	✓	✓
17.	LaMarre, Robson, & Dawczyk, (2015) [82]	✓	✓			✓	✓
18.	Lichenstein, McDonough, & Matura, (2013) [63]	✓	✓		✓	✓	
19.	Male, Fergus, & Stephen, (2015) [40]		✓		✓	✓	✓
20.	McKechnie, Barker, & Stott, (2014) [35]	✓	✓	✓		✓	
21.	Mohd Roffeei, Abdullah, & Basar, (2015) [85]	✓				✓	
22.	Oser, Oser, McGinley, & Stuckey, (2017) [64]	✓				✓	✓
23.	Perron, (2002) [65]	✓	✓		✓	✓	
24.	Reinke & Solheim, (2015) [66]	✓	✓	✓	✓		
25.	Russin, & Ferrell, (2019) [67]	✓				✓	

26. Sillence, Hardy, Briggs, & Harris, (2016) [76]		✓				✓
27. Solli, Bjørk, Hvalvik, & Hellesø, (2018) [84]	✓	✓		✓	✓	
28. Stjernswärd, & Hansson, (2014) [79]	✓	✓		✓	✓	✓
29. Stjernswärd & Ostman, (2010) [80]	✓	✓		✓		
30. Sullivan, (2008) [68]	✓	✓				✓
31. Vaughan, Trail, Mahmud, Dellva, Tanielian, & Friedman, (2018) [69]	✓					
32. White & Dorman, (2002) [70]	✓	✓		✓	✓	
33. Widemalm, & Hjärthag, (2015) [81]	✓	✓			✓	✓
34. Wilkerson, Brady, Yi, & Bateman, (2018) [71]	✓			✓	✓	✓

Appendix 2A: Search strategy

Key word search terms and database subject headings applied to each database (combined using Boolean operator “OR” within terms and “AND” across terms)

Search term category	**Key word search terms**	**PSYCINFO** **(subject headings)**	**CINAHL** **(subject headings)**	**MEDLINE** **(subject headings)**	**SOC INDEX** **(subject headings)**	**WEB of Science**
Online	“Web-based” OR “online” OR “internet” OR “digital” OR “social media” OR “social network” OR “Facebook” OR “blog” OR “forum” OR “app”	"Social Media" OR MM "Online Social Networks" OR MM "Digital Media"	MM "Social Media+" OR MM "Online social networking"	MH “Social Media”	DE “SOCIAL Media”	No subject headings
Peer support	“Peer* support” OR “social support” OR “support groups”	MM "Social Support"	MM "Support, Psychosocial+ "	MM “Social Support+”	DE “SOCIAL support” OR DE “SOCIAL networks”	No subject headings
Caregiver	“Carer*” OR “caregiver*	MM "Caregivers"	MM "Caregivers"	MH “Caregivers”	DE “CAREGIVERS”	No subject headings

Section Three: Critical Appraisal

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1. Overview

1.1 The process of appraisal

This critical appraisal aims to summarise the personal reflections I noted in a journal throughout the process of completing the research paper ("the Study") and systematic literature review ("the Review"). Recording my observations proved helpful in identifying potential influences and biases; gaining perspective on limitations and future research opportunities; and appraising the impact of the research on my future practice as a clinical psychologist.

1.2 Summary of research

The Study was a component of an NIHR funded project ("IMPART") which analysed data from a range of sources about the implementation of the Relatives' Education and Coping Toolkit ("REACT") in the NHS [1]. The Study aimed to explore the implementation of REACT [2] from the perspective of the end-user, relatives of people with psychosis or bipolar disorder, and identify the factors which impacted on their engagement. Interviews were conducted with 23 participants and data were analysed qualitatively. Thematic analysis resulted in 3 overarching themes: (i) motivation to understand and be understood; (ii) personal relevance sustains engagement; and (iii) usability and interaction enhance engagement. Findings highlighted that positive engagement factors were characterised by human interaction and the perception that REACT was personally relevant. The requirement for a thorough understanding of the needs of the caregiver was emphasised, together with the importance of involving service users in developing an intervention which reflects this.

The study also indicated that the design of digital health interventions (DHIs) should recognise the value that end-users place on the ability to interact online with peers and the importance of this as an engagement factor. The desire expressed by the participants to connect with others in the same situation was very strong and further emphasised by their frustration that REACT's online forum was not very well populated. This motivated me to explore caregivers' use of online peer support in the Review.

The Review synthesised qualitative findings about how caregivers of people with physical or mental health conditions engage with online peer support and the function it serves for them. Following a systematic database search, 34 studies were retained for inclusion. Thematic synthesis resulted in 2 overarching themes which represented the function of online peer support for the participants: (i) meeting caregivers' needs for a new type of sustaining friendship; and (ii) creating a space to express uncomfortable emotions. It was concluded that caregivers find connecting online with peers beneficial in terms of social support, emotional support and the exchange of information which helps them in their caregiving role.

1.3 Areas of appraisal

My reflections resulted in two key areas of critical appraisal. The first focussed on a similarity between the Study and the Review as both papers highlighted the limitation surrounding accessing the views of caregivers who choose not to engage online. The second area of reflection focussed on the underlying nature of the research and highlights the contrast between the two papers, as the Study was a component of the IMPART project which involved collaborating with members of a research team whereas the Review was undertaken largely independently. A reflexive approach considers how this impacted the data collection and analysis, with the benefits and challenges evaluated. The appraisal concludes by summarising the implications of my reflections, for future research and my personal practice.

2. Caregivers who choose not to engage online

2.1 Challenges surrounding accessing the views of non-engagers

The findings of both the Study and the Review highlighted the isolation and need for support experienced by caregivers. Connecting with other caregivers online through public social media platforms or forums integrated with interventions offers a way of meeting this need. The Study showed that caregivers appreciated the advice contained within video clips featuring other caregivers facing similar challenges, and that there was a strong desire to communicate with peers through a forum. The Review reinforced these findings, showing that online peer support mitigates isolation and provides an empathic space for sharing emotions. The breadth of the Review suggests that this applies to a range of health conditions and caring relationships. However, both the Study and the Review noted the difficulties involved with seeking the views of caregivers who choose not to engage with online support.

Most of the findings synthesised in the Review were derived from data available on public websites, which by their nature only captured material from caregivers who were actively engaged. Whilst studies featuring interview or focus group data highlighted some barriers to accessing online peer support such as fears about security and medical misinformation [3] exploration of the barriers was minimal. This represents a limitation as increasing knowledge about how caregivers engage with online resources requires an understanding of what causes them to disengage or reject this method of accessing support and information.

Despite a targeted recruitment strategy, it was only possible to interview 3 caregivers who were invited to use REACT but chose not to, to explore their feelings about online support. It is logical to conclude that if the concept of REACT is unappealing, engaging caregivers to discuss this and online support in general presents challenges. However, obtaining a more balanced sample of participants could have been prioritised earlier in the recruitment process, as the amendment which allowed caregivers who chose not to access REACT to be approached was processed relatively late in course of IMPART (January 2018). In order to capture detailed views about internet use in general and online healthcare, more extensive focus group research involving caregivers could have been conducted in conjunction with the Study, and this remains an opportunity for future research. However, it is recognised that recruiting hard to reach participants remains challenging. Whilst the utility of social media has been recognised as a method of recruitment with potential for extensive reach [4] this would not achieve an unbiased sample for the purpose of exploring attitudes to online interventions.

The Review highlighted that caregivers access support online in a variety of formats including FaceBook, Whatsapp groups, forums facilitated by charities and blogs. Understanding the motivation for selecting a certain format would assist in the development of supportive interventions. In addition, investigating the factors which contribute to ongoing engagement with online health provision is relevant [5, 6], and a follow-up study to explore this with REACT could be informative in understanding usage patterns.

Evaluation of the limitation surrounding barriers to accessing the views of caregivers who choose not to engage with online interventions or prefer different formats of online interaction led me to consider a group of potentially further marginalised caregivers. This group is characterised by caregivers who perhaps do not have the option of easily accessing the internet due to factors such as literacy, disability or economic hardship. Whilst this group is likely to be small given statistics indicating high levels of internet use in UK households [7], there is a risk that caregivers in these circumstances become even harder to reach and support as the focus on internet delivered interventions increases.

The acute distress and isolation described by some of the caregivers I interviewed as part of the Study highlighted the challenges they had faced alone and their need for support.

The Review emphasised the pervasive nature of this need across conditions and caring relationships. The caregivers I interviewed were in contact with clinical services and had been offered REACT as a source of support, and I considered caregivers who potentially had no contact with services, no social support and a reluctance or inability to access the internet. In addition to a lack of investigation of negative views about online peer support, the studies included in the Review did not acknowledge further marginalised caregivers and the potential consequences of their isolation in terms of the impact on mental and physical health.

2.2 The impact of the COVID-19 pandemic

The outbreak of the coronavirus disease 2019 (COVID-19) and its declaration by the World Health Organisation (WHO) as a pandemic has led to a significant shift towards online healthcare provision, which has seen barriers such as clinician and patient acceptance overcome rapidly in response to need [8]. Implementing and integrating an online health intervention in clinical services has been shown to be challenging and time consuming [9-11]. However, the unprecedented consequences of COVID-19 have meant that in many cases there has been no alternative but to provide a remote offering via the internet [12, 13]. The increased reliance on online communication has also been pervasive across work, education and social contexts due to social distancing guidelines. It is likely that the context of the global pandemic will permanently alter attitudes and behaviours surrounding interacting online, and this is a key area of future research. However, it feels important to remain mindful of the existence of a group of people for whom engagement online may not be acceptable or possible, and the consequences of this.

3. **Research context**

3.1 Background influences and reflexivity

My second area of reflection and appraisal focussed on the contrast between the Study, which was embedded in a larger project, and the Review which I conducted independently. In line with a reflexive approach to research [14, 15], it felt important to fully consider the context of the Study and the influences of this on my data collection and analysis. I had been involved in the design of REACT and the grant application for IMPART during my role at Lancaster University prior to starting clinical psychology training. I felt invested in REACT having conducted focus groups with caregivers and NHS staff about its content and design and felt strongly about the need to provide caregivers with support and information. Researching implementation theories and the knowledge practice gap [11, 16] relating to DHIs meant that I felt motivated to investigate how REACT could be embedded in the NHS.

Being part of a large research team with the potential to impact the provision of support for caregivers emphasised the feeling of purpose and motivation. However, I was aware that this context could influence my data collection and analysis. My aim was to be fully aware of the influences rather than to minimise them as this was consistent with a reflexive thematic analysis approach, which acknowledges that themes are developed actively rather than emerging from the data as descriptive themes [17]. Prior to data collection and analysis, I reflected on my expectations for the data and made a note of these. During data analysis I referred to my notes and considered the impact of my expectations. I was conscious that I hoped that relatives would find REACT beneficial, both in format and content due to my previous input to its development. Whilst my aim was to be aware of influences rather than mitigate them, recognition of this issue enabled me to attend fully to negative feedback about REACT. Equally, awareness of this helped me to remain focussed on the implementation process as well as evaluations of REACT itself.

I was also aware that a randomised controlled trial (“RCT”) to determine the clinical and cost-effectiveness of REACT was taking place at the same time as the IMPART study [2]. This built on an earlier feasibility trial where REACT in paper booklet format was shown to be effective in reducing relatives' distress and improving perceived support and ability to cope [18]. The latest RCT included 800 participants with high levels of distress at baseline who were randomised to receive either REACT or an online resource directory. I was conscious that my expectation was that there would be a significant reduction in distress at follow up in the participants who had received REACT, and this expectation underpinned the importance of understanding and optimising the implementation plan for REACT. However, the findings of the RCT showed that whilst there was a reduction in distress in both groups after 24 weeks, there was no significant difference between the groups [2]. It could be argued that this has repercussions on the IMPART study as REACT may need further modifications in order to improve its efficacy prior to being implemented across the NHS. The RCT concluded that research into the effectiveness of the individual modules of REACT is needed in order to assess which components are valuable to relatives and to further develop these [2]. The findings from the Study could be used in support of this research due to the strong indication that relatives valued the elements of REACT which featured other relatives, and their strong desire to connect with peers online through the forum. The findings of the Review emphasise this due to the perceived benefits of online peer support.

The RCT also reported that relatives found REACT safe, acceptable and convenient [2], which indicates that DHIs have potential as a source of information and support. In addition, the findings of IMPART have standalone value in their contribution to knowledge about the process of implementing a DHI in clinical services. For example, the relatives' data analysed in the Study indicated that the introduction to REACT should come from a trusted member of staff who is familiar with REACT's features and how it meets relatives' needs. Findings from the staff data analysed as a component of IMPART indicate that DHIs should be developed, evaluated and implemented in tandem with staff in the services they aim to support [19].

Conducting the research with attention paid to reflexivity and documenting my reflections and decisions as I progressed, revealed that whilst the reflexive process of self-interrogation was challenging and frustrating at times it supported the clarity and authenticity of the findings. Transparency about the researcher's position and potential biases is considered essential to the evaluation of qualitative research [15] and involvement of the wider IMPART research team provided a forum to discuss and justify my decisions. This also supported me in maintaining momentum and crystallising ideas when the reflexive process threatened to become overly introspective at the expense of progressing with the research, which is recognised as a potential pitfall of reflexive activity [20]. Literature highlighting that reflexivity is always a component of qualitative research and that the researcher's influence impacts the production of knowledge [14] resonated with me and a constructionist epistemology and emphasised that reflexivity was not a matter of choice. Probst (2015) proposes a method of appraising reflexivity and evaluating my research against the criteria provided reassurance that I had considered the key aspects specified [21]. For example, my background was considered in terms of the agenda of the research; the data analysis process included intersubjectivity with opportunities for review and the perspective of others; and self-interrogation was evident in the analysis as anomalies and contradictory data were presented.

I also reflected on the personal influences which impacted on the production of this thesis. I have had experience of caring for a family member who suffered the sudden onset of a serious health condition, which created significant emotional strain and had a negative effect across many aspects of life including family relationships, social interactions and work. Adjusting to the situation was challenging and required rapid absorption of knowledge about the condition and treatment. There was limited support available for families and caregivers at the time, which led to feelings of frustration and isolation. My personal experiences of caregiving and the impact this had on the extended family had a profound effect on me. Whilst this helped me to show empathy to the participants I interviewed in the Study, the main effect of my experiences was to drive my motivation to produce the Study and the Review and maintain my focus on the hope of increasing knowledge about how to support caregivers of people with mental and physical health conditions.

My experiences also meant that I appreciated the importance of the practical aspects of the delivery of caregiver support and the potential appeal of a flexible online solution. I have experience of seeking information and about health issues from online forums, which I have found valuable in terms of connecting with people in similar situations. My experiences resonated with some of the accounts expressed by participants in the studies included in the Review, and a commitment to reflexivity enabled me to maintain transparency about the potential influence of this on the development of the thematic synthesis.

3.2 Caregiver input to the Study

The involvement of service users was a key feature of the development of the REACT intervention and IMPART [1], and I was fortunate to have the input of two caregivers to the Study as service user researchers. It is recognised that public and patient involvement in research is critical to ensuring that health services meet the needs and preferences of those they are designed to support [22], and the impact of my own personal experiences reinforced this. Prior to data collection the service user researchers took part in pilot interviews which allowed me to practice the semi-structured interview format and prepare for conducting interviews over the telephone. Whilst it was recognised that interviews conducted face-to-face have advantages over those conducted over the telephone, such as visual cues which aid communication and rapport building [23], the wide geographical spread of the IMPART study and timeframes precluded this in most cases.

Constructive feedback from the service user researchers related to my style as an interviewer which at times was perceived to be more aligned with a therapist role than a researcher. This has been highlighted as a key ethical issue for clinical psychologists who conduct research, and it is recommended that individuals who fulfil this dual role reflect on the contrasting purpose of therapy to that of research [24]. Whilst the communication skills required of a clinical psychologist enabled me to build rapport, I remained mindful that the purpose of the interviews was to gain knowledge. I used supervision to maintain this focus which proved helpful when faced with participants' intense and emotive descriptions of their experiences as caregivers. Discussions with the service user researchers also facilitated consideration of the power relations between researcher and participant [15]. Whilst the role of interviewer carries a certain degree of power, I recognised the participants also had a powerful role in shaping and creating knowledge, underpinned by a social constructionist epistemology. Reflections on the interviews also illuminated the contrast between the interviews I had conducted myself and those conducted by other members of the IMPART team. I had detailed memories of my interviews and I recognised that the process of reflexive analysis had started during the interview. Acknowledgement of this focussed my attention on full and detailed consideration of all the interview transcripts to maintain awareness of potential bias towards interviews I had conducted myself.

The service user researchers also input to the data analysis as we worked collaboratively to analyse 6 interview transcripts, discussing the content and potential meanings in detail. In line with Braun and Clarke's (2019) [17] guidance we aimed for a collective, rich and nuanced reading of the data rather than seeking consensus. The service users' perspective was particularly illuminating in providing caregivers' views on interacting with services and the importance of feeling that caregivers' needs are recognised and understood, with resources available to attend to them. The focus on the reflexive nature of the analysis of the relatives' data was also helped by discussions about the contrast between the inductive thematic analysis of the relatives' data and the theory driven (Normalisation Process Theory, [25]) approach used for the analysis of data collected from NHS clinical staff as part of the IMPART study [19]. Ongoing awareness of this contrast helped me to remain mindful that whilst the IMPART study required relatives' views on specific aspects of the implementation process, prioritising their voices about the experiences of being offered and using REACT was a key tenet of the Study.

In contrast with the experience of being part of a research team and working with service users, I conducted the Review independently (with guidance from my supervisors). This had advantages in terms of immersing myself in the work without the logistics of coordinating with a wider team, but it also had limitations. Whilst my aim was to investigate caregivers' use of online peer support across a range of caregiving relationships, health conditions and online formats, this meant that the database searches returned many potential papers. It would have been helpful to have worked with a second researcher to discuss decisions about papers for inclusion, particularly due to the variety of studies returned from the searches in terms of methodology and data sources. Working collaboratively to screen papers for inclusion recognises the subjectivity of decisions and the value in debate to reach a consensus [25]. The Review contained 34 studies, which took considerable time to analyse and quality appraise. The input of a second researcher to this process, particularly the quality appraisal, could have led to more detailed insight into the quality and characteristics of the underlying studies and recommendations for the design of future research.

Consideration of reflexivity with regard to the Review and reflecting on the process ensured that I attended to the biases surrounding the background to the research as the selection of the topic was underpinned by the findings of the Study which in turn was motivated by the IMPART project [1]. Recognition that I was affected by the Study participants’ strong desire to connect with other relatives online meant that I remained open to data which contradicted this. Whilst the Review lacked an element of intersubjectivity, highlighted as beneficial to reflexivity [21], I remained committed to self-interrogation throughout the process, which was evident in my discussion of data which was anomalous to sub-themes presented.

Consideration of reflexivity also extended to consideration of the studies included in the review and it was notable during the quality appraisal process that reference to reflexivity was absent from most of the studies. This resonates with the findings of a systematic review which investigated the use of the Critical Skills Appraisal Programme (CASP) [26] to evaluate qualitative studies about individuals’ experience of back pain [27]. Nineteen studies were included in the review, none of which discussed reflexivity [27]. However, whilst reflexivity may not be overtly discussed the research may still have been conducted with consideration given to reflexively, with the recommendation that studies are evaluated for the appropriate discussion of the research agenda, process, intersubjectivity and self-interrogation by the researcher as evidence of attention paid to reflexivity [21].

4. Conclusion

The process of reflecting on and appraising my work has highlighted the importance of recognising the interrelatedness between research and clinical practice, as interventions should be developed with consideration of their implementation to ensure that they are integrated in services and ultimately the intended end-user benefits from new knowledge. This has influenced my plans for my future practice, as I will take up a clinical role, I am keen to remain involved in research activities throughout my career. Involvement in IMPART has emphasised the importance of involving service users in the development, evaluation and implementation of new interventions.

Consideration of reflexivity has increased my awareness of personal influences on all aspects of the research process, including interactions with participants and the analysis of data. My understanding of the process and impact of reflexivity has been enhanced by working in a research team which provided a forum for debate and the need to justify decisions made. Evaluating reflexivity as part of the quality appraisal of the studies included in the Review has reinforced its importance as a component of qualitative research.

Conducting the Study and the Review increased my awareness of the challenges associated with being a caregiver and I will continue to draw on this when working with clients clinically. I will fully consider the family and system the client is part of and the dynamics of the relationships that form it. My research has also highlighted the difficulties surrounding connecting with and researching hard-to-reach populations, and the potential for isolated caregivers to experience distress without access to support. It feels important to acknowledge the existence of this minority group, so the challenges surrounding accessing their views for research purposes do not lead to their needs being overlooked.

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Section Four: Ethics

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Summary of the ethics approval process for the Research Paper

The research paper submitted as part of this doctoral thesis formed a component of a National Institute of Health Research (NIHR) funded study, "*Implementation of an online relatives' toolkit for relatives of people with psychosis or bipolar experiences: the IMPART multiple case study*"[1, 2]. Approval for the relatives' qualitative data to form the Research Paper of this thesis was submitted to the NHS Research Ethics Committee (REC) on 17/12/2017 as an Amendment to the original IMPART approval, approved by Lancaster University as Sponsor. This was approved by the REC on 26/01/2018, and the Health Research Authority (HRA) on 21/02/2018. The Integrated Research Application System (IRAS) application for the Amendment follows. The IMPART study protocol is included at Appendix 4A. The Participant Information Sheet, Consent Form, Interview Topic Guide and Recruitment Flyer are included at Appendix 4B, 4C, 4D and 4E. The REC approval is included at Appendix 4F and HRA is included at Appendix 4G.

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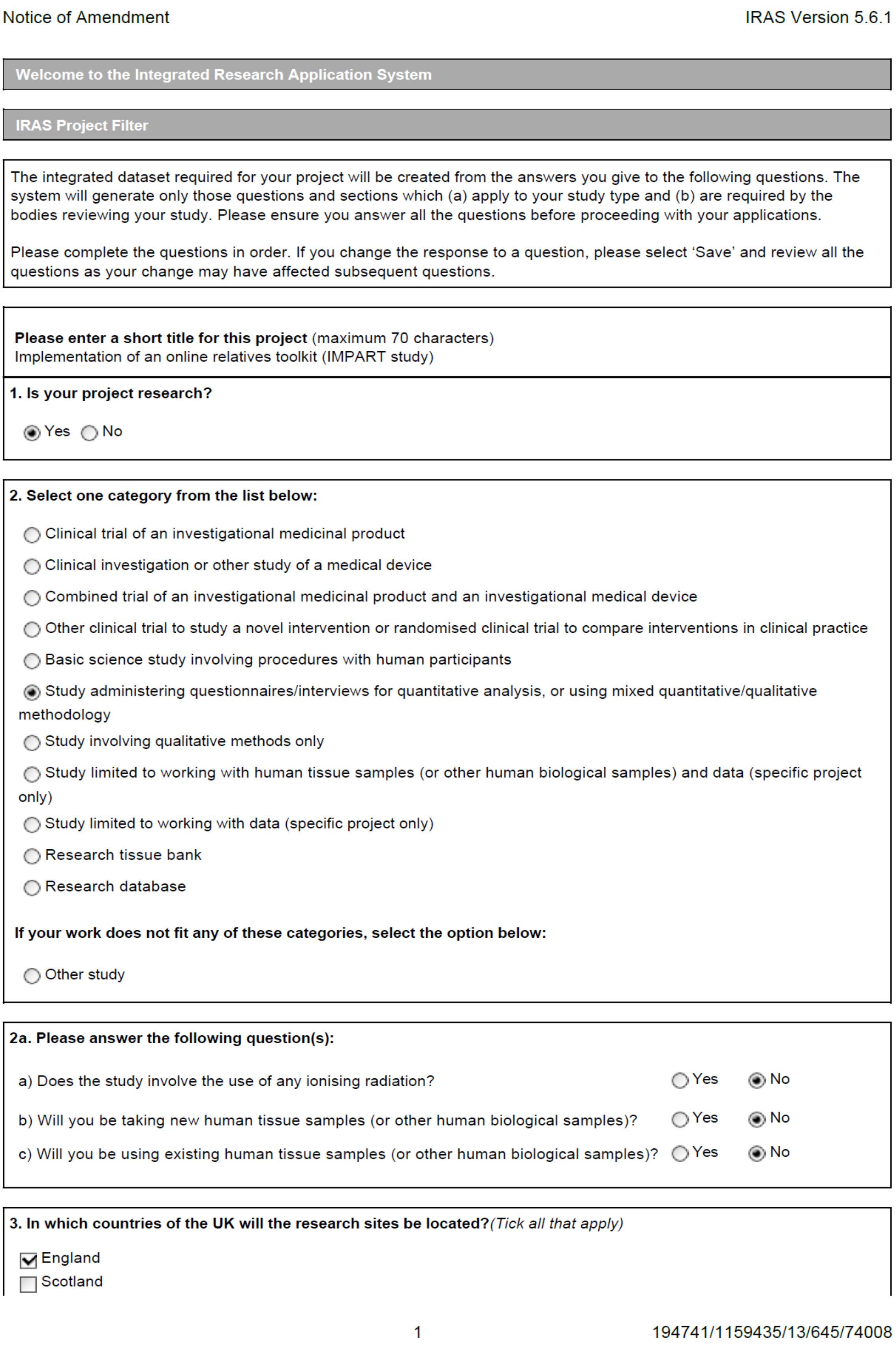
IRAS ethics application



Notice of Amendment

IRAS Version 5.6.1

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select ‘Save’ and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Implementation of an online relatives toolkit (IMPART study)

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

● Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

○ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	● No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	● No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	● No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☑ England
☐ Scotland

☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

● England
○ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☐ IRAS Form
☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ Her Majesty's Prison and Probation Service (HMPPS)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

○ Yes ● No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

● Yes ○ No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

○ Yes ● No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ● No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ● No

9. Is the study or any part of it being undertaken as an educational project?

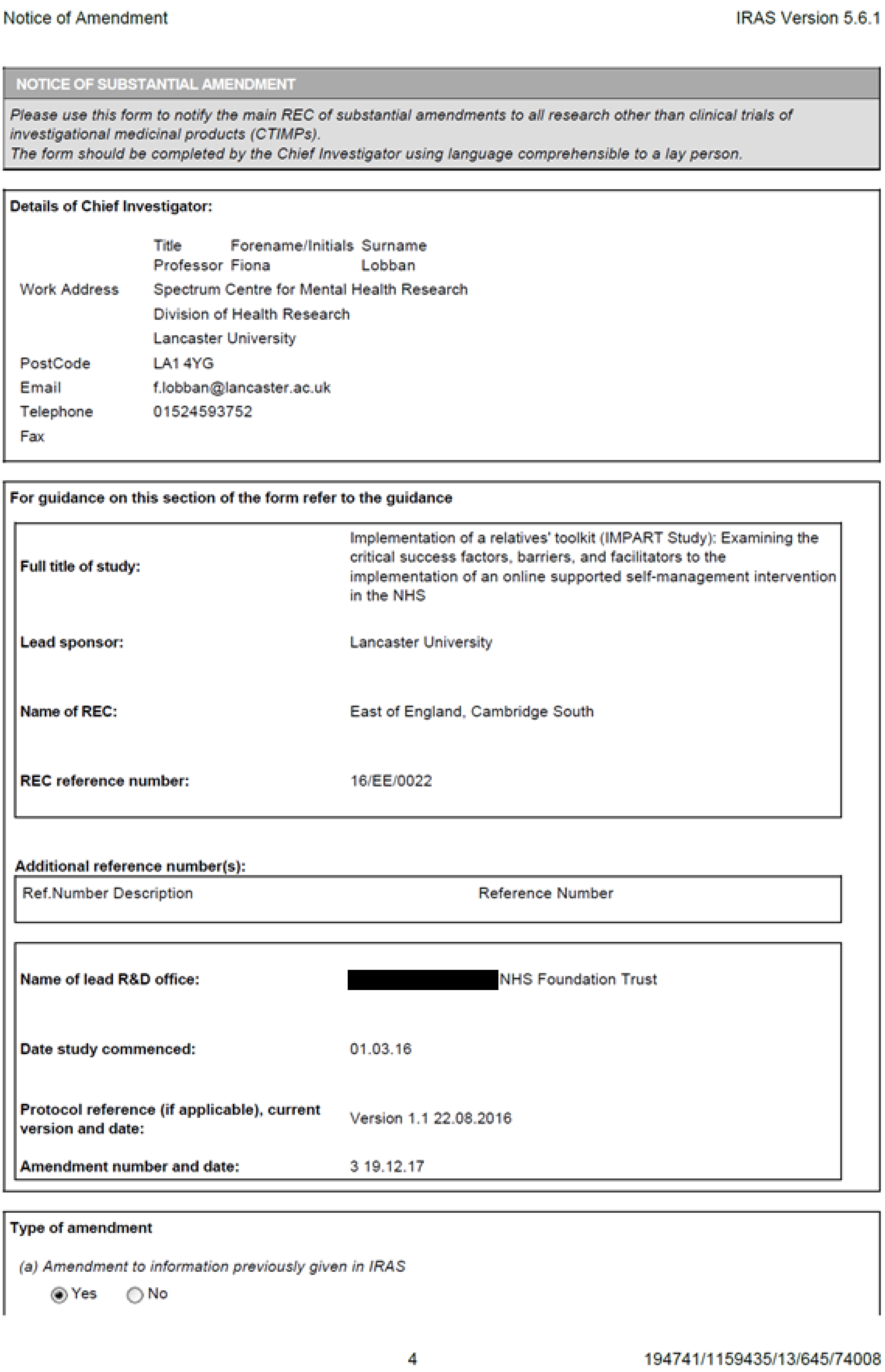
○ Yes ● No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ● No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ● No



NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
	Professor	Fiona	Lobban

Work Address Spectrum Centre for Mental Health Research
Division of Health Research
Lancaster University
PostCode LA1 4YG
Email f.lobban@lancaster.ac.uk
Telephone 01524593752
Fax

For guidance on this section of the form refer to the guidance

Full title of study:	Implementation of a relatives' toolkit (IMPART Study): Examining the critical success factors, barriers, and facilitators to the implementation of an online supported self-management intervention in the NHS
Lead sponsor:	Lancaster University
Name of REC:	East of England, Cambridge South
REC reference number:	16/EE/0022

Additional reference number(s):

Ref.Number Description	Reference Number

Name of lead R&D office:	[redacted] NHS Foundation Trust
Date study commenced:	01.03.16
Protocol reference (if applicable), current version and date:	Version 1.1 22.08.2016
Amendment number and date:	3 19.12.17

Type of amendment

(a) Amendment to information previously given in IRAS

● Yes ○ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

IRAS sections referred to below.

(b) Amendment to the protocol

● Yes ○ No

If yes, please submit <u>either</u> the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

Revised protocol with new version number and date submitted, changes highlighted in text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

● Yes ○ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Revised documents with new version numbers and dates submitted, changes highlighted in text.

Is this a modified version of an amendment previously notified and not approved?

○ Yes ● No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

This request seeks approval for the following amendments, all of which relate to the process of recruiting relatives and collecting relatives' data:

IRAS form question A27-1 and A-29. Approval is sought to contact relatives who have previously been invited by EIS clinical staff to access the REACT intervention but have not created a REACT account, in order to invite them to take part in an interview. The study protocol (section 6.7 – data collection) has been amended as highlighted, to reflect this. It is considered important to explore the experiences of relatives who have not accessed REACT in order to capture the reasons behind this and enhance understanding of the implementation process. The interview topic guide has been amended to reflect this. We seek approval for this group of relatives to be contacted by EIS clinical staff or by NIHR clinical research network representatives (by email, face to face, telephone or post, with one initial contact and one follow up contact). Relatives who decline to take part in an interview will not be contacted again.

IRAS form question A27-1 and A-29. Approval is sought for a small amendment to the way in which relatives are invited to take part in the data collection for the IMPART study. Rather than having to go through the process of deciding whether to take part, complete consent, and all the measures before they can have a look at the toolkit, we would like to separate the data collection process from the use of the toolkit. Participants will now receive a separate email inviting them to take part in the data collection, once they have responded to their invitation to use REACT, with response options included as links in the email giving the relative the choice of finding out more about the research study, being contacted about taking part in an interview, or declining to take part in the research. This change is proposed in response to direct feedback from relatives, in that they wanted to be able to see REACT before deciding about the research, and that some were confused and believed that by completing the measures, they had used REACT. They did not click through to the toolkit after doing the measures. By collecting data separately to use of the toolkit, we will hopefully overcome this confusion. There are no changes to the text inviting relatives (it has only moved from the website to an email), or to the PIS or consent form. Section 6.7 of the protocol has been amended as highlighted to clarify this process.

IRAS form question A18. Approval is sought to where possible, offer relatives who are to be invited to take part in an individual interview the option of taking part in a focus group discussion instead or in addition to an interview, as it is felt that some relatives may prefer to talk about their experiences of the implementation of the REACT intervention in a group setting together with other relatives, rather than an individual interview. Offering the flexibility of format allows relatives to share their views in the way they are most comfortable, and facilitates the capture of a wider range of implementation data. Focus Groups would take place in a clinical, university or community setting, would last for a maximum of 2 hours, would be facilitated by at least 2 members of the IMPART research team, and would include a maximum of 10 relatives per group. A focus group Participant Information Sheet, Consent Form and Topic Guide have been drafted and are included within this application. The protocol has been amended to include references to focus groups in addition to relatives' interviews.

IRAS form question A29. Approval is sought to include a flyer in the recruitment materials for relatives in order to provide a short summary of the opportunity to be involved in the IMPART study through participating in an interview (or Focus Group). This flyer would be delivered by post or email to relatives who have been introduced to REACT, through EIS staff and NIHR CRN representatives.

IRAS Form filter question 9. Approval is sought for a part of the study, the relatives' interviews, to form an educational project. This educational project will be undertaken by Johanna Barraclough, a third year student on the doctorate in clinical psychology programme at Lancaster University as her doctoral thesis, to be submitted in August 2018. Johanna Barraclough is an employee of Lancashire Care NHS Foundation Trust, and has Letters of Access to conduct research in each of the 6 NHS Trusts involved in IMPART. The project will involve Johanna managing the data collection and analysis of the relatives' interviews, will follow the IMPART study protocol and will be supervised by Professor Fiona Lobban, who will remain as CI. The additional IMPART study output comprising of a doctoral thesis has been highlighted as an amendment to Section 7 of the Protocol (Dissemination and projected outputs).

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Participant Information Sheet (relatives) Focus Group	1	12/12/2017
Consent form (relatives) Focus Group	1	12/12/2017
Topic Guide Focus Group	1	12/12/2017
Topic Guide (Relatives Interviews)	1.1	12/12/2017
Flyer	1	12/12/2017
Protocol	1.2	12/12/2017

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Dr Fiona Lobban on 19/12/2017 15:31.

Job Title/Post:	Professor of Clinical Psychology
Organisation:	Lancaster University
Email:	f.lobban@lancaster.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 20/12/2017 08:30.

Job Title/Post:	Head of Research Services
Organisation:	Lancaster University
Email:	y.fox@lancaster.ac.uk

Appendix 4A: IMPART study protocol

Study Protocol (Version 1.2)

Title: IMPlementation of A Relatives' Toolkit (IMPART study): Examining the critical success factors, barriers and facilitators to implementation of an online supported self-management intervention in the NHS

1. Summary of Research

An iterative case study design, conducted across six NHS Trusts, will identify the critical success factors, barriers and facilitators to implementation of an online supported self-management intervention in the NHS. The Relatives' Education And Coping Toolkit (REACT) is an evidence-based online supported self-management intervention for relatives of people with recent onset psychosis, which has been shown to significantly reduce distress and increase perceived ability to cope (22). The intervention was co-produced with relatives, is recovery focussed (www.IMROC.org), and offers an effective way for mental health services across the UK to meet the new 2014 NICE Guideline for psychosis recommendation to provide an education and support programme to relatives. Trusts offering REACT to relatives are also provided with an online REACT Training Package for the supporting staff which provides them with clear guidance and materials to support relatives to use REACT. Previous NICE guidelines (2009) have recommended that relatives are supported through structured Family Intervention. However, NHS Trust surveys estimate that only 1 – 17% of families have received this (4-6). It is therefore vital that the 2014 guidelines are more successfully implemented. Supported self-management interventions, delivered using interactive technology, supported by clinical staff, are becoming an increasingly popular way to deliver cost effective healthcare to people with chronic needs (28, 29) but implementation of these approaches in routine clinical practice is poorly understood. This study will produce a national Implementation Plan for REACT, but the relevance of the findings more broadly will also be articulated to inform wider implementation of self-management interventions in health services.

Our research employs a theory driven case study design (30). This will allow us to understand the process of implementation of REACT within a real-world setting, and to identify the causal factors which determine how well this process works (or not). Based on this approach, we will first introduce REACT to all Trusts during phase 1. All trusts will be provided with a preliminary Implementation Plan (IP version 1) which will include a presentation about the rationale for REACT and clear guidelines on how it should be used by staff. This timing is to coincide with the start of the evaluation of access and waiting times guideline that EI teams in NHS Trusts will be required to follow http://www.england.nhs.uk/wp-content/uploads/2015/02/mh-access-wait-time-guid.pdf. It is important that Trusts have a plan in place to meet the target to deliver NICE Concordant care – including information and support to carers by April 2016. (Phase 1, 1-6 mos). Alongside this we will outline an implementation theory about the factors we think will influence successful implementation of REACT, and generate hypotheses about the mechanisms by which they will lead to successful outcome. To do this we will conduct: (1) a systematic review of relevant implementation studies of NHS based interventions to ensure we build on previous knowledge; (2) analysis of data relevant to implementation from the feasibility trial; (3) stakeholder workshops across all participating Trusts; (4) a synthesis of this data informed by our clinical and theoretical expertise in this area. This learning will also inform the items for a Fidelity Scale which will be used by within individual Trusts to assess the extent to which the key components of the Implementation Plan are being delivered. The Fidelity Scale design and development is informed by previous research evaluating implementation of Evidence Based Practice (31). We will then test and refine these hypotheses using an iterative comparative case study design across 6 NHS Trusts (Phase 2, 7-24 mos). Data will be collected from multiple sources and analysed initially within each Trust. Finally (Phase 3, 25-30 mos), we will synthesise data across all Trusts to develop a national Implementation Plan for REACT. We will draw out broader conclusions which can be used to inform implementation of other supported self-management interventions across the NHS, and inform the further evolution of implementation theories.

Our implementation theory is informed by Normalisation Process Theory (NPT). This theory has been successfully used in a wide range of NHS implementation studies and provides a practical framework to guide data collection (www.normalizationprocess.org/). NPT facilitates generation of specific hypotheses about the process by which a complex healthcare intervention is implemented, embedded and integrated (or not), that can be tested empirically, and has previously been applied in ehealth settings (32).

Success of implementation will be assessed by the uptake and use of REACT by relatives at each Trust. We will also evaluate the impact of REACT on relatives' distress and wellbeing to test Trust specific effectiveness, and the resources required for implementation at each Trust.

The study will be conducted across 2 geographical sites (North and South of England), with 3 Trusts at each site that will be purposively sampled. This will increase theoretical generalisability of findings across NHS Trusts, whilst allowing research staff employed at each site to manage data collection across Trusts. Detailed case study data will be collected and analysed in two NHS Trusts participating in wave 1 (1 in the North and 1 in the South) to identify the key barriers and facilitators to implementation using IPv1. This analysis will be used to develop a revised Implementation Plan (version 2), and a refinement of our implementation hypotheses. These hypotheses will then be tested using the revised IP which will be introduced to a second Trust at each site (wave 2). Data collection and analysis across these two Trusts will then focus on further hypothesis testing, following which a further iteration of the Implementation Plan will be developed (version 3). This will be introduced to the final Trusts (wave 3), and data from these Trusts, will inform the final draft.

This design means that

1- We ensure that all Trusts receive access to the intervention within the timeframe required by NHS England monitoring of access and waiting times.

2. We can capitalise on the valuable opportunity to specifically explore the impact of a significant contextual change (introduction of this monitored standard on access and waiting times) on support for carers – and specifically also on implementation of a digital intervention to support relatives (REACT). Variation between sites will provide important data on factors which influence implementation.

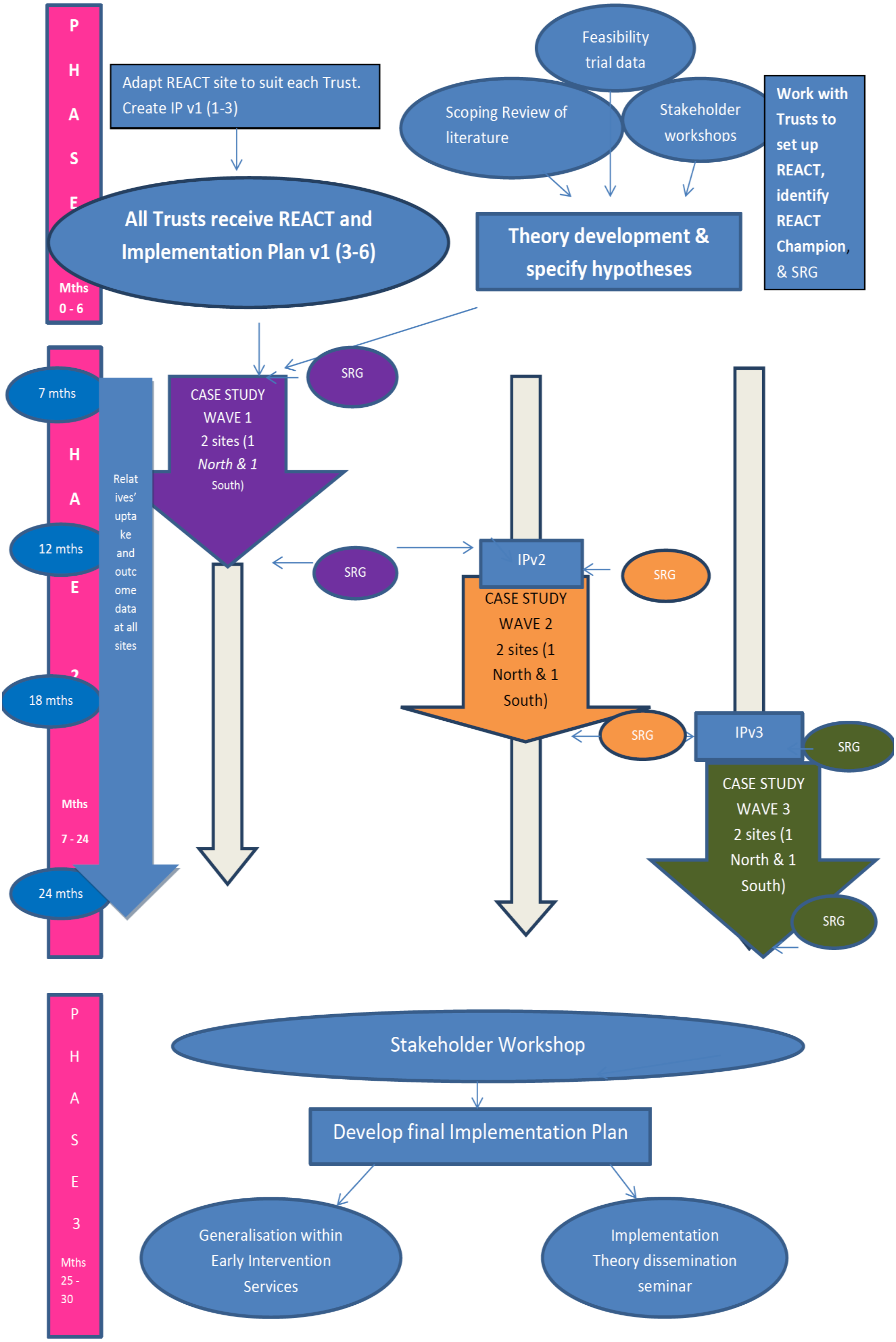
3. We can identify factors that impact on implementation at all stages including initial implementation, embedding and integration.

This design is informed by our clinical experience that implementation can be delayed in NHS settings for many reasons, and therefore it is important that we collect data at both the start of the implementation process, but also continue to see what factors influence whether the intervention is successfully retained and becomes integrated into routine clinical practice in the longer term.

Data sources at each Trust will include observation of naturally occurring meetings, document analysis, stakeholder reference groups and stakeholder in depth interviews and focus groups. Data will be analysed first within each Trust, providing useful data to participating Trusts to inform future service development plans. In Phase 3 we will synthesise data across Trusts to develop the national Implementation Plan. Analysis and synthesis will be done with input from the entire project team, including Stakeholder References Groups (SRGs) at each site to ensure a co-produced plan with shared ownership.

The exact nature of the Implementation Plan cannot be determined at this stage but will include: a video rationale for the use of REACT including research and policy context; a step-by-step guide to successful implementation of REACT; a Fidelity Scale to enable Trusts to self-monitor fidelity to the

Implementation Plan; online REACT supporter training toolkit; a summary of resources needed to implement REACT; measures/evaluation tools to evaluate uptake and outcome for relatives; case examples describing the process of implementation across participating Trusts – where the focus is on identifying and overcoming key barriers. Wider applicability will be tested in a larger conference / workshop with stakeholders from none participating Trusts who will be presented the data and invited to further contribute to the development of the plan and broader implementation theory.


P H A S E
Mths 0 - 6
Adapt REACT site to suit each Trust. Create IP v1 (1-3)
Feasibility trial data
Scoping Review of literature
Stakeholder workshops
Work with Trusts to set up REACT, identify REACT Champion, & SRG
All Trusts receive REACT and Implementation Plan v1 (3-6)
Theory development & specify hypotheses
H A E 2
Mths 7 - 24
7 mths
12 mths
18 mths
24 mths
Relatives' uptake and outcome data at all sites
SRG
CASE STUDY WAVE 1 2 sites (1 North & 1 South)
SRG
IPv2
SRG
CASE STUDY WAVE 2 2 sites (1 North & 1 South)
SRG
IPv3
SRG
CASE STUDY WAVE 3 2 sites (1 North & 1 South)
SRG
P H A S E 3
Mths 25 - 30
Stakeholder Workshop
Develop final Implementation Plan
Generalisation within Early Intervention Services
Implementation Theory dissemination seminar

2. Background and Rationale

This research addresses the problem that relatives of people with psychosis are not currently receiving the support and information they need, despite the existence of evidence based interventions (2) and the fact that supporting relatives is an explicitly stated government policy recommendation (8) and a key recommendation of the NICE Guideline for psychosis and schizophrenia (34). Relatives provide the vast majority of care, saving the NHS an estimated £1.24bn per year in the UK (35), but this caring role is associated with high levels of distress in relatives (36,37), significant practical, financial and emotional burden (38), stigma, worry, shame and guilt (39), trauma (40), and loss (41,42). Despite the clear need for support, research shows that delivery of recommended interventions to relatives by the NHS is very poor (4-6). A better understanding of the barriers to supporting relatives is vital. This study aims to address this problem by conducting a detailed investigation of the process of implementing a supported self-management intervention which has already been demonstrated to be effective in improving outcomes for relatives of people with psychosis. Identification of the factors which support successful implementation of REACT across multiple NHS Trusts creates new knowledge which is directly relevant to NHS Trusts in complying with NICE Guidelines, and has the potential to lead to changes in practice which can have a direct positive impact on all relatives of people with psychosis (approximately 620,000 relatives) in NHS services across the UK. The findings from this study will also inform improved implementation of other supported self-management interventions across the NHS, and contribute to the growing literature identifying ways to overcome the significant barriers to the translation of research findings into clinical practice. A lot of money is spent on developing and testing new health technologies, but there is conversely very little understanding of how they are successfully implemented in routine clinical practice (1).This study fits the HS&DR remit to produce evidence regarding the quality, accessibility and organisation of health services.

3. Evidence explaining why research is needed now

There is an urgent need for this research as although evidence based interventions for relatives exist, and NICE Guidelines state that relatives of people with psychosis should be supported, relatives' access to interventions is limited and inadequate. A Cochrane systematic review (2) demonstrates the efficacy of family interventions in improving outcomes for people with psychosis, and a further recent systematic review (3) has demonstrated that family interventions can also improve outcomes for relatives. However, audits of NHS Trusts indicate that the majority of relatives do not access family interventions (5). The recent Schizophrenia Commission report (42), summarises the inadequacies in the provision of NHS care for families of people with psychosis, and makes the key recommendation that improving support for relatives and involving them as partners in care should be a national priority. To facilitate implementation of NICE guidelines, the new "Guidance to support the introduction of access and waiting times standards for mental health services in 2015/2016" commits NHS Trusts to ensuring more than 50 per cent of patients experiencing their first episode of psychosis will, from 1 April 2016, access NICE concordant care within two weeks of referral. The impact of this is yet to be seen, but will be assessed within our study design.

Throughout the NHS there is a growing interest in the development of self-management approaches as a clinical and cost-effective way to deliver healthcare. However, there is also recognition of the urgent need to understand how new interventions are implemented in clinical services (44). Without this, there is a danger that money is wasted on developing new technologies which are never successfully implemented and the gap between evidence and practice becomes ever wider. NIHR has funded the development and evaluation of REACT (PB-PG-0807-14075) which can be made available nationally. To ensure it makes a real difference to people, we now need to understand how this intervention can be successfully implemented in clinical services. This study will specifically inform a national Implementation Plan for REACT, but will also offer a basis for understanding more broadly the factors impacting on implementation of supported self-management interventions across the NHS – especially those delivered online. Recent plans to extend the national IAPT Program (Increasing Access to Psychological Therapies) in England to severe mental illness has led to a scoping exercise to identify evidence based, structured, interventions such as REACT. Understanding facilitators and barriers to the implementation of these will be crucial in determining the successful rollout of such national programs.

4. Aim

The study aims to understand the critical success factors, facilitators, barriers, and resources needed to integrate an online supported self-management intervention for relatives of people with recent onset psychosis into routine clinical care, and to use this information to develop a national Implementation Plan. Findings from this study will also be used to develop the growing evidence base investigating the translation of research findings into clinical practice, particularly regarding supported self-management interventions in mental health.

5. Objectives

Objectives are to:

(i) Measure the uptake and use of REACT by NHS EIS teams and relatives.

(ii) Identify the critical success factors, facilitators and barriers to implementation of REACT.

(iii) Identify the resources (and costs) needed for successful implementation of REACT in EIS teams.

(iv) Investigate the impact of REACT on self-reported relatives' outcomes.

(v) Develop a user friendly REACT Implementation Plan and related resources (inc Fidelity Scale) to facilitate widespread use and dissemination within the NHS.

(vi) Use the findings from this study to further develop theories of implementation of supported self-management interventions in the NHS

6. Research Plan

6.1 Design and theoretical / conceptual framework

REACT intervention

The REACT intervention was designed to meet the needs of relatives and close friends of people with psychosis. REACT consists of an online toolkit with support to use the toolkit offered by a supporter in the EIS using telephone or email. The development of the REACT intervention was informed by (i) a systematic review of interventions reporting on outcomes for relatives of people with psychosis (3); (ii) a series of focus groups with relatives, co-facilitated by a relative (45); (iii) clinical and personal expertise within the research team (consisting of relatives, clinicians, and academics); and (iv) extensive feedback from service users and relatives throughout the development process. The toolkit is comprehensive and modular in format so that the content is divided into manageable sections which can be used flexibly depending on the individual needs of the relative. These include: Introduction to REACT; What is Psychosis?; Managing Positive Symptoms; Managing Negative Symptoms; Dealing with Crises; Dealing with Difficult Behaviour; Managing Stress – Thinking Differently; Managing Stress – Doing Things Differently; Understanding Mental Health Services (how to get the help you need); Treatment Options; The Future; Resource Directory; Jargon Buster. Modules range in length between the equivalent of eleven and twenty-three A5 pages, though the Resource Directory is considerably longer at forty-three pages. The Resource Directory can be edited to include relevant local resources as well as those available nationally.

Although the information is about people with psychosis in general, the toolkit is designed to help relatives to make this information specific to their family by identifying key questions they may need to ask to get the information they require. Case examples are used extensively to aid illustration. The content of the toolkit reflects the key ingredients in existing evidence based family interventions. All relatives are given a code to allow them to access the REACT site. Each participant is supported in the use of the toolkit by a trained member of the clinical team. Trusts can identify the most appropriate supporters, given their staff resources and structure. However, we have designed the support to be offered by a non-professional support worker (or equivalent e.g. Assistant Psychologist/Graduate Mental Health Worker) currently working in an EIS team. They are well placed to offer the level of support required for this self-management approach as it does not require highly trained health professionals, but does require availability and flexibility. Importantly, they are also relatively inexpensive thereby avoiding cost barriers to further dissemination. Support workers (also referred to as STR workers – as they offer Support, spend Time with service users and promote Recovery) generally work alongside Care Coordinators to offer practical support to ongoing psychosocial interventions. They primarily work with people experiencing psychosis (rather than relatives). They are generally not trained health professionals but require an interest in working with people with mental health problems, and an ability to demonstrate good basic listening and communication skills. They will have attended mandatory Trust training. They will be also trained to use REACT using standardised training materials provided by the research team. In the initial Implementation Plan (v1) these materials will include an outline of the background and rationale for REACT, and clear guidance on how to use the toolkit. These materials will be developed further in each subsequent iteration of the Implementation Plan, in response to learning about what facilitates implementation. The training recommends that relatives are offered an initial session in which they are introduced to the toolkit (either face to face or over the telephone). Support is then offered by email or telephone or direct messaging through the website (Trusts can decide which form of communication they can best support and whether they can offer relatives a choice) for a maximum of 1 hour per week over 6 months (though in the pilot the median total minutes of support per relative over the 6 months was 125 (IQR = 75-204). To ensure communication is maintained, supporters are asked to contact relatives monthly as a minimum if relatives do not respond to appointments or initiate any contact. Support is targeted at helping relatives to identify the key difficulties they face and guiding them to find the most relevant information and strategies in the toolkit. Discussion then focuses on making these general principles as directly relevant as possible to each individual relative, and helping relatives to try out new strategies and reflect on the impact of these. The toolkit and the support are designed to make the intervention enactive rather than symbolic i.e. it encourages relatives to actively practice new skills, rather than just providing information. The training builds on existing clinical skills of the support workers and focuses on the key areas of motivation to engage with the toolkit, active listening and empathy, identification of key problem areas, and how to support relatives to use the toolkit to best meet their specific needs. REACT was very well received in the pilot study (qualitative and quantitative data) and in response to specific feedback, we have included video clips of relatives sharing their experiences, updated information in the resource directory, and increased the interactivity of the website throughout. We now wish to examine how this intervention can be successfully implemented into routine clinical services.

Theoretical framework

There are many theories relevant to implementation of research into practice. The use of theory is important in helping to generate hypotheses based on the theory about what might be important mechanisms underlying the implementation process. This allows us to structure our data collection framework to test these theories, rather than collecting masses of data with no clear focus. It also ensures that learning from this project is generalised to a broader understanding of implementation science through development of the theory.

However, we are keen that our theory should be used as a guide and will not blind us to ignoring other important processes that are apparent through either our feasibility data, or in our data collection at each NHS Trusts.

There are several models, frameworks, and theories we could have used to guide our work. We originally proposed the PARIHS framework which has been widely applied in health care settings (46). However, whilst PARIHS identifies key determinants which act as barriers and facilitators to implementation (specifically evidence, context, and facilitation), and is based on extensive testing and development in healthcare settings, the framework does not offer a theory about the how change happens, or causal mechanisms underlying the implementation process. Nor has it been applied specifically to the adoption of ehealth interventions. We are interested in both of these, and so have chosen to use Normalisation Process Theory (NPT) as our theoretical guide.

NPT began as a model (NPM) of the factors that promote or inhibit the routine work of embedding a new health technology into practice. The key constructs identified were: interactional workability; relational integration; skill-set workability; and contextual integration. The model has since been developed into a theory which includes the NPM as constituting “collective action” and adds concepts of “coherence” (how actors make sense of a set of practices); “cognitive participation” (the means by which they participate in them); and “reflexive monitoring” (how these practice are then appraised).

The theory facilitates generation of specific hypotheses about the process by which a complex healthcare intervention is implemented, embedded and integrated (or not), that can be tested empirically, and has previously been applied in ehealth settings (32). Thus it can act as a guide to focus our data collection and hypothesis testing, whilst also allowing us to develop the theory in light of our findings. Alongside Prof Rycroft-Malone, who is a national expert in implementation science, our team also includes Professor Elizabeth Murray who has worked extensively to develop NPT and its application to ehealth interventions.

Design

Our research employs a theory driven multiple case study design (30). This will allow us to understand the process of implementation of REACT within a real-world setting, and to identify the causal factors which determine how well this process work. Based on this approach, we will first outline a programme theory about the factors we think will influence successful implementation of REACT. This will be based on NPT and facilitated by tools available on the NPT website which can guide this process (www.normalizationprocess.org/). We will generate hypotheses about the mechanisms that will lead to successful outcome, and we will then test and refine these hypotheses using an iterative case study design. Case studies can provide rich detailed data, and are particularly useful when trying to understand the implementation of a complex intervention in a real life setting in which the process cannot be controlled. REACT is a "complex intervention" (47) because it depends on the actions of individuals, across a range of different contexts, and adapting their behaviour over time. It also produces multiple outcomes which need to be understood. Implementation is made more complex by the context in which the intervention is situated, which is dynamic and includes competing demands on the system. A mixed methods approach including quantitative assessments of outcome (delivery and use of REACT), and qualitative assessments of mechanisms including observation, document analysis and in-depth interviews and focus groups is therefore required to attempt to capture and make sense of this complexity. We have also designed the study to have extensive input from stakeholder groups at each of the participating Trusts to ensure that the Implementation Plan is truly co-produced and reflects the needs of the stakeholders.

Phase 1 –We will develop our theory of implementation of REACT and generate specific hypotheses based on this. The theory will be informed by Normalisation Process Theory. Specific hypotheses will be informed by:

1. A systematic review of relevant implementation studies to ensure we build on previous knowledge. The exact focus will be determined by a scoping exercise but our focus will be on

implementation of new interventions specifically within community mental healthcare settings. The review will begin in phase 1 with a scoping exercise to allow the literature to inform our study early on. However, given the scale of work, the full review will be ongoing throughout phase 2.

2. Analysis of data collected during the feasibility trial which was conducted across 3 NHS Trusts in the North West of England. Data collection in the trial did not focus specifically on implementation issues, but REACT was supported in the study by staff already working within the EIS teams, and detailed supervision notes were made. Many of the issues arising in supervision pertained to implementation issues which offer important insights relevant to developing our implementation theory including: clarity of the REACT supporter role; integration of this role into existing workload; understanding of REACT across other team workers; organisational support for REACT in terms of time allowed for training and delivery. This data will be reviewed to identify factors relevant to successful implementation
3. Stakeholder workshops within and across Trusts. These workshops will serve 3 functions
    a. Develop good working relationships with key stakeholders at each Trust including commissioners, service managers, clinical staff, service users and relatives. This group will form a Stakeholder Reference Group (SRG) at each Trust.
    b. Finalise an initial plan (version 1) to facilitate the implementation of REACT, including the rationale and process of integrating REACT into the existing service, and the resources needed to do this. This will include design of a Fidelity Scale to assess fidelity to the Implementation Plan
    c. Generate hypotheses about what the stakeholders believe will be the key facilitators and barriers to the implementation of REACT.

During Phase 1 we will also provide all Trusts with the REACT site and a basic implementation plan (version 1).

Phase 2 –We will use an iterative case study design to collect and analyse data to test our hypotheses about what factors will influence implementation of REACT.

1. Detailed case study data will be collected and analysed to test our implementation hypotheses at the first 2 Trusts in wave 1 for the first six months. During this time, the data will be used to develop a revised Implementation Plan and Fidelity Scale (version 2), and to refine our implementation hypotheses.

2. The revised Implementation Plan (IPv2) will then be introduced to a second Trust at each site (wave 2), and further data will be collected here to test the impact of this and to identify additional factors which are impacting on the longer term embedding of the intervention . Data collection and analysis across both of these Trusts will then focus on further hypothesis testing, following which a further iteration of the Implementation Plan will developed (IPv3).
3. Version 3 of the Implementation Plan will be introduced to the final Trusts at each site (wave 3), and data from this wave, combined with longitudinal data from the ongoing four Trusts from wave 1 and wave 2 will inform the final draft.

It is difficult to anticipate in advance the ideal number of iterations to develop an Implementation Plan, but we have proposed 3 waves, providing in-depth data from 6 NHS Trusts as our research experience suggests this will provide sufficient depth of understanding across a range of different settings, whilst ensuring the data collection and analysis is manageable within the timeframe and resources requested for the study.

The Implementation Plan will include a Fidelity Scale. This will be developed as part of the iterative case study process. Consistent with previous guidance (31), the scale items will reflect the key principles underlying REACT and procedures identified for successful implementation (identified during phase 1&2). Items are rated on a 1-5 scale from no adherence to full adherence, and average score computed. The measure will be used during the study to identify the extent to which each component of the intervention is being successfully implemented within each participating Trust, and direct data collection. The scale will be developed iteratively during the study as additional key components are identified and areas of poor implementation are investigated.
The final version of the Fidelity Scale will be included in the Implementation Plan and will allow Trusts to self-monitor adherence to the key principles and practices of REACT which have been identified as crucial for successful implementation and outlined in detail in the Implementation Plan. Research has shown this process of self-monitoring can facilitate sustained use of a new intervention (31).

An important consideration throughout the study is the need to clearly record and interpret the role of the research team in the process of implementation. Our aim is to move from a very basic Implementation Plan (version 1) which is informed by our theory about what is likely to influence the implementation process, to a more sophisticated national Implementation Plan at the end of the study which addresses the barriers identified during the study. We acknowledge the problems inherent in the research team both evaluating and also being part of the implementation process, but we believe that without this involvement, it would not be possible to understand the implementation process in the depth and detail needed for this case study design. We will ensure that our data collection is transparent and clear records are kept of what the actions of the research team in facilitating implementation so that this can be incorporated into the analysis. In repeatedly taking the data back to the broader SRGs at each site, and at key points throughout the study, we will ensure sufficient critical distance on our interpretation of all of the data, including our own role in the implementation process.

Phase 3 –We will develop the final Implementation Plan, assess wider applicability for other supported self-management interventions in the NHS, and draw out implications for further development of implementation theory.

1. Data will be analysed in a series of stages to inform the final Implementation Plan.
    a. Within each Trust, data will first be analysed within data set (meetings, documents, interviews or focus groups), and then synthesised across these data sources. The initial analysis will be done at a coding level by the researcher, with input from the research team to identify key themes and to develop the analysis framework.
    b. Within each Trust these frameworks will be presented in a workshop setting to the SRG within the Trust who will input into a synthesis of data across the data sources, and to draw out the key recommendations from the data that can be used to inform the Implementation Plan.
    c. In the final stage, data will be synthesised across Trusts. This will be done by inviting members of the participating Trust SRGs to a central meeting at which the key themes across all the data sources at each of the Trusts will be presented. A similar process of discussion will focus around identifying the key recommendations for a national Implementation Plan which will highlight common implementation factors likely to be relevant to all Trusts, but also variability, and include recommendations of ways in which implementation of REACT can be adapted to suit the specific needs of the Trust.
2. Generalisability of the findings will be explored in two ways:
    a. Stakeholders from EIS teams in non-participating Trusts will be invited to attend a workshop in which they will be presented with the REACT intervention, and the final Implementation Plan. This workshop will be co-delivered by the research team and members of the participating Trust SRGs. Presentations will include the research data, and case examples from participating Trusts. Attendees will be encouraged to use the

knowledge and experience of the facilitators to develop a plan for how they can implement REACT in their individual Trust. They will be encouraged to ask questions and explore the hurdles experienced at participating sites, and find out how these were overcome.

b. We are also interested in the broader relevance of these findings for implementation of other supported self-management interventions in mental health services. There is a rapid increase in the development of such approaches, but to date, no attempt to address the implementation challenges. We will organise a second dissemination event in which the audience will be stakeholders from mental health services (not restricted to EIS teams), and academics and clinicians interested in implementation science. We will present the study findings, drawing out broader implications for other self-management interventions, and for implementation theory. Output will be written up for peer review publications.

6.2 Sampling

Sampling is important at two levels in this project: Trusts; and data sources within each Trust. A framework at each level is based on theoretical sampling i.e. what sample do we need to ensure we get the data required to test our hypotheses. A formal statistical power calculation is not appropriate for this design, but careful sampling will provide sufficient variability to ensure a widely applicable Implementation Plan.

a. Trusts

Purposive sampling of Trusts will ensure variation across key factors including geographic location (North/South), and population (urban/suburban/rural; social deprivation; ethnic diversity). Our participating Trusts consist of varying numbers of EIS teams, with different organisational structures. These are likely to impact on the process of implementation (e.g. supporting relatives with culturally diverse models of psychosis) so it is important that our Implementation Plan is designed to accommodate this variation. We have identified 6 eligible Trusts, 3 in the North of England, and 3 in London/South which we feel best capture this variation. Additional teams have expressed an interest and are reserve options at this stage. Feasibility data provides an estimated population of 150-200 new relatives referred to each Trust per annum. Our implementation period covers 18 months in 6 Trusts giving a total study population of approximately 1350-1800 relatives.

b. Data sources within each site

Data sources will include observation of naturally occurring meetings, document analysis, Stakeholder reference group focus groups and in-depth interviews with stakeholders. The selection of data sources will be informed by the specific hypotheses being tested i.e. we will seek out data which is best placed to help us test our hypotheses. We will ensure that data is sampled from across different levels of the organisations including (a) strategic planning, (b) management and delivery, (c) service users & relatives. Meetings and documents that directly relate to REACT, or to aspects of the service relevant to supporting relatives will be targeted. Where hypotheses suggest particular factors such as staffing levels, or availability of supervision, are important, then meetings and documents that are likely to pertain to these factors will also be analysed. The SRG at each site will help to determine the meetings and documents most relevant at each stage. Examples of relevant meetings are likely to include Trust Board meetings; Adult Mental Health Quality and Performance Meetings; CQUIN target strategy; EIS business and clinical meetings; Carer's Strategy meetings; PPI strategy meetings. Relevant documents are likely to include Trust Annual Quality Accounts; Psychosis Pathway; EIS Commissioning Spec and Operational Policy; CQUIN reports, Carers Strategy, Trust website and service user information leaflets; Complaints and SUI investigations; Service user and carer feedback.

In-depth interviews will also inform our analysis. Based on past experience we anticipate conducting approximately 20 interviews at each Trust with key people from relevant stakeholder groups including service commissioners, service managers, supporters, relatives and service users. Relatives will be offered the opportunity to take part in an individual interview or a focus group together with other relatives. Ensuring we sample all our data sources across different levels of the organisations, and across the full data collection time period in each Trust, we are confident this data sample should provide the breadth and depth of data we need to test our hypotheses.

6.3 Setting/context

This study will take place in Early Intervention Services (EIS) in the NHS in England (or teams with an equivalent function). EIS teams represent a highly accessible and universal point of access to mental health services for people experiencing first episode psychosis through a range of different referral routes including NHS, voluntary sector and self-referral. They support service users and their relatives. EIS teams were set up in response to good evidence of a "critical period" during the first 3 years of illness during which intervention is thought to be particularly effective in preventing longer term disability Most teams work with people aged 14- 35 who have developed symptoms of psychotic illness for the first time, for a period of up to 3 years following first contact (though exact criteria vary between services). EIS teams generally consist of a mix of psychiatrists, psychologists, care coordinators (social workers, community psychiatric nurses, occupational therapists) and support workers.

6.4 Data collection

Data collection will require a mixed methods approach. We acknowledge that all methods have limitations, but used together, they strengthen the validity of the findings (48). At each site, the following data will be collected to address each of the study objectives.

Quantitative measures will be used to assess the uptake and use of REACT by NHS EIS teams and relatives (objective 1), to investigate the impact of REACT on self-reported relatives outcomes at each site (objective 4), and to investigate the resources (and costs) needed for successful implementation of REACT (objective 3) . Specifically, we will assess the number of REACT accounts created for relatives to access the REACT site, and the level of use of each module using web analytic statistics. We will collect basic demographic information about all relatives on the site to audit which users the intervention is actually reaching. In addition, we will ask care coordinators to provide non-identifiable summary data relating to the number of relatives on their caseload who were not offered the toolkit and the number of relatives who were offered the toolkit but declined, and brief reasons why relatives were not offered or declined the toolkit. Relatives who were offered the toolkit but declined, or did not subsequently access REACT will be invited by EIS staff or NIHR CRN representatives to take part in an interview or focus group to discuss their experience of being offered REACT. No identifiable patient data will be transferred to the research team for relatives who declined or were not offered the toolkit, or who declined or did not respond to the invitation to take part in an interview or focus group. Relatives who choose to visit the site will also be invited by email to take part in the collection of outcome data, and will have the choice of completing questionnaires, taking part in an interview, or both. Following online consent, they will complete questionnaires to assess levels of distress (General Health Questionnaire-28; wellbeing (Carer Wellbeing and Support Scale); quality of life (EQ5D-5L) ehealth literacy (eHEALS); about their caring role; and to provide feedback on the REACT site. The measures were shown to be acceptable and sensitive to change in the feasibility trial. They will be offered at baseline and again after 12 and 24 weeks to ensure we capture short and longer term impacts within the timeframe of the study. Those who do not wish to take part in the outcome measures can still receive the REACT intervention and contribute anonymously to the implementation data. Resources will be identified using proformas designed specifically for this study. We will generate a list of the likely resources involved as part of Phase 1, and design measures to record this at each site. The proformas will be flexible to accommodate any additional resources identified during the process of data collection. Our team has considerable experience of collecting this kind of data using adapted versions of the Client Service Receipt Inventory (CSRI) which employs a similar approach to recording service input and then calculating cost using unit prices (49). All data from relatives will be downloaded to a database held at the CTU. Data to identify the critical success factors, facilitators and barriers to implementation of REACT (objective 2), will be primarily qualitative and will consist of:

A. Stakeholder Reference Groups. The SRGs were initially proposed to be purely for consultation purposes and to inform data collection within the trusts and feedback on findings. However, after the first wave of SRGs their important contribution to understanding key factors relevant to implementation was apparent and so the SRG meetings will be transcribed and thematically analysed for research purposes. All participants will be aware of this at the point of recruitment and ask to consent accordingly.

B. Interviews with key stakeholders (commissioners, managers, frontline clinical staff, relatives, and service users). Semi-structured interviews will be conducted face to face (preferably) but over the phone if needed. Focus groups (with up to 10 other relatives) will be offered to relatives as an alternative to individual interviews. We anticipate conducting up to 6 focus groups (1 per Trust), with focus groups facilitated by at least 2 members of the research team. The topic guide will focus on identifying facilitators and barriers, and testing hypotheses re implementation. Interview and focus group schedules will be open enough to allow new ideas to emerge, but will also target specific issues hypothesised to be important. Based on past experience we anticipate conducting approximately 20 interviews at each Trust. All interviews and focus groups will be transcribed in full and coded using NVivo software to aid data management.

C. Document analysis-. Documents are most likely to provide data related to the context in which REACT is being implemented, but are likely to also cast light on the facilitation process. Examples of relevant documents are likely to include Trust Annual Quality Account; Psychosis Pathway; EIS Commissioning Spec and Operational Policy; CQUIN reports, Carers Strategy, Trust website and service user information leaflets; Complaints and SUI investigations; Service user and carer feedback. Interpretation of the contextual data from individual Trusts will be helped by comparison to nationally available data where possible, including the Mental Health

Minimum Data Set (MHMDS) and National Audit for Schizophrenia (NAS). This will allow relative comparison of caseloads, referral rates, and duration of untreated psychosis (DUP).

D. Observation of naturally occurring meetings will be recorded using proformas developed for the study and designed to capture the relevant information to test our hypotheses in each context. Examples of relevant meetings are likely to include Trust Board meeting; Adult Mental Health Quality and Performance Meetings; CQUIN target strategy; EIS business and clinical meetings; Carer's Strategy meetings; PPI strategy meetings.

We will be careful to ensure that we sample all our data sources across different levels of the organisations, and across the full data collection time period in each Trust.

6.5 Data analysis

1. Data will be analysed in a series of stages to inform the final Implementation Plan.
    a. Within each Trust, data will first be analysed within data set (SRG focus groups, meetings, documents or interviews / focus groups), and then synthesised across these data sources. The initial analysis will be done at a coding level by the researcher, with input from the research team to identify key themes and to develop the analysis framework.
    b. Within each Trust these frameworks will be presented in a workshop setting to the SRG within the Trust who will input into a synthesis of data across the data sources, and to draw out the key recommendations from the data that can be used to inform the Implementation Plan. During this process we will explicitly seek potential alternative interpretations of the data to maximise the validity of our findings
    c. In the final stage, data will be synthesised across Trusts. This will be done by inviting all members of the participating Trust SRGs to a central meeting at which the key themes across all the data sources at each of the Trusts will be presented. A similar process of discussion will focus around identifying the key recommendations for a national Implementation Plan which will highlight common implementation factors likely to be relevant to all Trusts, but also variability, and include recommendations of ways in which implementation of REACT can be adapted to suit the specific needs of the Trust.

Quantitative data will be analysed in order to present outcomes in a clinically meaningful way to individual Trusts. Relatives' outcomes will be compared statistically at the different time points using repeated measures analysis of variance with time as the independent variable.

Qualitative data analysis will be guided by the use of framework analysis (50). This pragmatic approach is particularly useful for applied research in which data is synthesised from different sources

The initial analysis will be within data sets (interviews / focus groups, documents, observations) and later synthesised across data sets. Our initial framework will be derived from both an initial process of familiarisation with the data, and informed by our programme theory,. We will use the framework flexibly, recognising that emergent data may inform further development of the framework

The exact nature of the final plan will depend on the data collected and the input of the SRGs, but will include:

1. a video rationale for the use of REACT including research and policy context;
2. a step-by-step guide to successful implementation of REACT;
3. a Fidelity Scale to enable Trusts to self-monitor fidelity to the Implementation Plan;
4. online REACT supporter training toolkit;
5. a summary of resources needed to implement REACT;
6. measures/evaluation tools to evaluate uptake and outcome for relatives
7. case examples describing the process of implementation across participating Trusts – where the focus is on identifying and overcoming key barriers.

6.6 Dissemination and projected outputs

The main outputs from this research are:

(1) A national Implementation Plan to include: a video rationale for the use of REACT including research and policy context; a guide to successful implementation of REACT; a Fidelity Scale to enable Trusts to self-monitor fidelity to the Implementation Plan; Online REACT supporter training toolkit; a summary of resources needed to implement REACT; measures/evaluation tools to evaluate uptake and outcome for relatives; case examples describing the process of implementation across participating Trusts – where the focus is on identifying and overcoming key barriers.

(2) A workshop to facilitate the uptake of REACT by none participating EIS teams;

(3) A dissemination event focussing on development of theory underlying implementation of supported self-management interventions within the NHS that can be used to inform service development in other clinical areas where supported self-management interventions are being used for people with long term health conditions and their carers.

All outputs will be widely disseminated to all relevant stakeholders including NHS Trusts, national EI network (IRIS), service users, relatives, clinical academics and the general public. A website already exists which was developed for the pilot study and is being successfully used to disseminate findings from the pilot. This website will provide updates and outputs from the study and links to all publications and presentations – www.reactclinic.co.uk .

Journal articles outlining the main findings will be written for open access in academic journals (such as Health Services & Delivery Research Journal, BMJ, BJP), leading implementation science and service development journals (such as Implementation Science, Health Services Research, Psychiatric Services, Journal of Medical Internet Research). Publications aimed at service users and carers will be targeted at appropriate web and print forums (such as Carers UK, Your Voice (Rethink), Pendulum (Bipolar UK)). All articles will be adapted to suit the relevant audience and input from the whole research team will ensure these are accessible, appealing and informative.

Findings from the relatives' interview and focus group data will be written up as a doctoral thesis by a doctorate in clinical psychology student, (Johanna Barraclough), supervised by the CI.

Findings will be presented at key national and international conferences in each of the stakeholder forums, for example to clinicians and academics at the RCPsych Congress, British Association of Behavioural and Cognitive Psychotherapy (BABCP), American Association for Behavioral and Cognitive Therapies (ABCT), International Early Psychosis Conference and Rethink Mental Illness conference. We will also target conferences specifically focussing on implementation issues such as Health Service Research (http://www.health-services-research.com/conference/) and Knowledge Mobilisation Forum.

To broaden dissemination as widely as possible, we will develop a social media strategy to promote our findings using twitter, facebook, and key mental health blogs (e.g. Mental Elf, Mental Health Today). We will build on links with carer networks to promote findings to local groups and work with national organisations such as MIND, Carers Trust, McPin Foundation, Rethink Mental Illness, and

Carers UK to promote findings on their websites. Finally, we will work with the Science Media Centre and University press offices to engage with the news media where possible. Although the intervention is currently written specifically for relatives in the NHS in England, it could easily be adapted to meet the needs of relatives in other countries. Our links with the International Society for Psychological and Social Approaches to Psychosis (ISPS) and International Early Psychosis Association (IEPA) will facilitate international dissemination. Since publication of the REACT feasibility trial, we have had interest from clinical teams from Norway and New Zealand and we are collaborating on Implementation Plans to help them adapt REACT for use in their own services.

The IAPT programme (Increasing Access to Psychological Therapies) is currently expanding from depression and anxiety to include more severe and enduring mental health problems including psychosis. The lack of supported self-management interventions has already been highlighted as a significant issue, especially given the success such approaches have had in increasing access to therapy for people with depression and anxiety. It is not clear to what extent "low intensity" interventions are suitable for service users with more severe mental health problems, but our pilot data suggest that supporting relatives with supported self-management interventions is highly acceptable and feasible, but not currently available. Filling this gap by developing REACT must be followed by ensuring it is disseminated within these organisations that will determine wide clinical use. Our research team include members of both the NICE Guideline Development Group (Johnson) and the IAPT Expert Advisory (Jones) and Training Task Groups (Lobban, Jones). Our team (Rycroft-Malone) also includes the Chair of the NICE Implementation Strategy Group which will ensure findings are also contributing to the advice this group provides on implementing Clinical Guidelines.

The main direct beneficiaries of this research will be relatives, who will receive the information and support they need and should be able to access, but currently are often unable to do so. As well as reducing distress and improving outcome for relatives, the intervention is likely to have a significant indirect impact on other family members including the service user. If relatives feel more able to cope, have more information and strategies to manage psychosis and are involved as partners in the care team, they are more likely to continue to care. There is good evidence that where relatives are involved, service users have a significantly improved outcome(6), and that working with families is a clinically and cost effective way to reducing frequency of relapse and hospital admissions, and improve social functioning for service users with psychosis (2, 34, 51). The other direct beneficiaries will be clinical staff, who by effectively engaging relatives as partners in care, make their own role more manageable. NHS Trusts will benefit from being able to meet their clinical targets to provide widely accessible support to relatives. Indirectly, the whole of society will benefit from the improved wellbeing of significant part of the population, and the costs saved by the improved mental health of service users and relatives. Given the potential generalisability of these findings to implementation of other self management interventions, and the potential for REACT to be adapted for relatives of people with other kinds of mental health problems, the indirect beneficiaries of this research are extensive.

7. Plan of investigation and timetable

Phase	**Time**	**Milestones**		
		Management	**Resources**	
Pre-start	**-4 – 0months**	Ethics, R&D, appoint key staff	Research team (unfunded)	
Phase 1 a. Theory development and specification of implementation hypotheses b. Offer REACT and Implementation Plan v1 to all Trusts	**Months 1-6**	Theory Development a. Scoping review b. Review of implementation data from the feasibility trial c. Stakeholder workshops in North and South d. Version 1 of Implementation Plan Development of IPv1 All Trusts given REACT and IPv1 Development of online system for data collection (NB adapted from REACT trial)	Research fellow x 2 – Stakeholder workshops at each site (1 North and 1 South)	
Phase 2 Case study data collection	**Wave 1** **7-24months**	2 x Trusts- ongoing data collection and analysis (stakeholder reference group held 6 monthly at each Trust)	2 x 2 stakeholder workshops	
	Wave 2 **12-24 months**	2 x Trusts- ongoing data collection and analysis (stakeholder reference group held 6 monthly at each Trust)	2 x 2 stakeholder workshops	
	Wave 3 **18-24 months**	2 x Trusts- ongoing data collection and analysis (stakeholder reference group held 6 monthly at each Trust)	2 x 2 stakeholder workshop	

	Ongoing implementation and relatives' outcome data collected at all Trusts		Online system for data collection (already set up for REACT trial)	
Phase 3 Finalise Implementation Plan and dissemination	**Year 3 months 25-30**	(a) Stakeholder workshop across participating Trusts (b) Workshop to facilitate generalisability to none participating Trusts; (c) Dissemination seminar for mental health service developers and implementation scientists, focussing on broader implications for supported self management interventions for long term mental health conditions. Final Implementation Plan Analysis of costing and resources	1Stakeholder workshops across Trusts 1 Generalisability workshop 1 Seminar	

8. Project management

The overall responsibility for the delivery of the project to time and budget will be held by the CI (Lobban). Her role is supported by the project team consisting of the co-applicants. The entire project team will meet every 3 months throughout the period of the study to monitor progress and problem-solve issues that arise (combination of face to face and teleconference).

A site researcher will be employed at the North site (supervised by site leads Jones & Lobban) and the South site (supervised by site lead Johnson). They will be integrated into established clinical research teams, providing access to broader clinical and academic infrastructure and peer support. Site leads will provide supervision to site researchers as required, but a minimum of fortnightly face to face meetings.

A senior IMPART lead will be identified within each Trust who will lead the collaboration between the research team and the Trust. This will be someone within the Trust who can identify and provide access to key data sources required for the study. They will meet regularly (approximately fortnightly) with the site researcher to facilitate access to data.

A Stakeholder Reference Group (SRG) will be set up at each of the participating Trusts. The role of this group is to ensure the perspective of all stakeholders is integrated into the research and to understand SRG members views about implementation of REACT to inform research outcomes. Groups will be set up during Phase 1. Configuration of the groups will be flexible, but will include the following stakeholders: Senior Trust Board members or service leads; team managers; support workers (x2); relatives(x2); service users(x2). Each group will be chaired by the PPI site lead (Minns in the North and Pinfold in the South) and co-facilitated by the Trust IMPART lead, and the researcher at each site. This group will meet at strategic points throughout the study and specifically at the outset and towards the end of each detailed case study. They will inform pre-implementation outcomes, implementation data synthesis and guide the process of iterative data collection to ensure hypotheses are generated and tested at each site.

Workshops and seminars to synthesise data across Trusts, and to explore generalizability to none-participating Trusts will be led by our EIS lead Professor Smith and facilitated by other members of the project team. Our Implementation Science seminar in which we will present the broader implications of the findings for other mental health services, and for the development of implementation theory, will be led by our implementation expert Prof Ryecroft Malone. Methodological guidance on statistics and collection of REACT delivery cost data will be provided by Sutton and Hollingsworth (co-applicants).

In accordance with the HS&DR Research Governance Guidelines, A Study Steering Committee will provide overall supervision for a project on behalf of the Project Sponsor and Project Funder and to ensure that the project is conducted to the rigorous standards set out in the Department of Health's Research Governance Framework for Health and Social Care and the Guidelines for Good Clinical Practice. Nominations are:
Chair: Professor David Kingdon, Professor of Mental Health Care Delivery at the University of Southampton, UK, and honorary consultant adult psychiatrist for Southern Health NHS Trust. He has previously worked as Medical Director for Nottingham Health Care Trust and Senior Medical Officer

(Severe Mental Illness) in the UK Department of Health. He now does policy and implementation work for NHS England and is editor of their mental health websites.

A Relative: to be recruited through the NIHR Clinical Research Network PPI database once funding is confirmed. This will ensure they are independent from members of the study team. I have contacted CRN who are happy to facilitate recruitment to this role and I have costed time for the post as directed by them at £150 per meeting (4 across the study), including all travel, preparation and tasks.

Senior Clinical Academic with relevant methodological expertise: Professor Gunn Grande, Professor of Palliative Care at the University of Manchester who brings expertise in health services research, and specifically real world exploration of how support is delivered to relatives, using a range of quantitative and qualitative approaches.

Senior NHS Manager in Early Intervention Services for Psychosis: Dr Erin Turner, Consultant Psychiatrist Early Intervention Service, Solihull, who is interested in the use of technology in clinical mental health services.

This study will be run in parallel with an NIHR HTA funded trial evaluating REACT offered to a broader range of relatives, outside the NHS, supported by Expert Relatives. A sub-group of the applicants (Lobban, Jones, Minns, Johnson, Murray and Liverpool CTU) will work across both studies to ensure complementarity and management.

9. Approval by ethics committees

Before the study commences we will gain ethical approval through the National Research Ethics Service (NRES), and the Sponsor (Lancaster University) and ensure we have NHS R&D approval at every Trust. All staff will have appropriate contracts, research passports, letters of access and have completed all mandatory Trust training. All staff will be up to date with training in Good Clinical Practice (GCP), taking informed consent (including for people lacking capacity), information governance training / information security, and assessing risk.

The site leads will oversee all data collection, storage, and management and ensure that this is anonymous and secure and consistent with the Data Protection Act (1998). Access will be restricted to preserve confidentiality and blindness.

Data collection occurs at two levels. Analysis of the process of implementation and contextual factors is largely based on observation and analysis of SRGS, meetings and documents and will be done with organisational consent, ensuring all staff are aware of the process, and reporting no individualised data. All staff in the Trust will be informed about the study, the rationale, and the process of data collection, and given the opportunity to ask questions prior to the start. Where the researchers are present in a meeting, they will be introduced at the start of the meeting with an explanation of their role. The researchers will have honorary contracts with the participating Trusts and will adhere to all confidentiality and data protection policies within the Trust. An audit of the number of REACT accounts generated, demographics of the users, and use of the website will be collected regardless of whether relatives consent to taking part in the IMPART study. Relatives' usage data will be collected to inform feasibility and acceptability outcomes including auditing the resources and costs to deliver REACT for each Trust, and understanding which population groups are being supported by this intervention.

The second level of data is individual interview / focus group and outcome data and this will require individual written informed consent for each participant.

We do not anticipate any significant risk to participants or staff. Data will primarily collected on NHS premises, but if any interviews are conducted off site, then lone worker policies of the research teams will be followed. Participant Information Sheets will direct people to independent sources of support for either emotional distress, or to raise any concerns about the research.

10. Patient and Public Involvement

This study has extensive PPI throughout all stages of the design and delivery. The original REACT feasibility trial had relatives involved within the research team as researchers, relatives were on the TSG and the project team included a co-applicant who is a relative of someone with a long history of schizophrenia who was also part of the research team in the feasibility trial for REACT (Minns: aka Chapman for the purposes of publication). The data collected within the trial provided a strong support that REACT was well received by carers. In this application we have the same relative as a co-applicant (Minns) and her role will be Public Involvement lead at the North site, matched by Pinfold (Director of the McPin Foundation to promote user involvement in research) at the South site. Pinfold was also involved in the original feasibility trial and runs the McPin Foundation charity that promotes best practice PPI in mental health research. Their role will be to represent the views and needs of service users & relatives throughout the research process, by drawing on their contacts within service user and carer networks and to Chair all of the Stakeholder Reference Groups (SRG) in each of the participating Trusts. Minns and Pinfold will ensure the SRGs have active involvement of service user and relative experts from each Trust, and support them to contribute to decisions within the study over what data to collect, content of the Implementation Plan, synthesis of findings and study recommendations. Both will also ensure that findings from the study are effectively disseminated to service user & relatives audiences. They will support the Trusts to ensure appropriate involvement of service users & relatives in the Stakeholder Groups, and provide training, supervision and support to these stakeholders around the process of research to maximise their input. We have costed for the time of the co-applicants and the input from of service users and relatives within the SRGs, and for additional analysis and dissemination time. We anticipate that involving relatives will improve the delivery of the project, the experience of relatives in the research process, and how effectively the findings are disseminated. This study has extensive PPI throughout all stages of the design and delivery.

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Appendix 4B: Participant Information Sheet

Interviews Participant Information Sheet (Relative)

Title of project: Implementation of a relatives' toolkit (IMPART Study): Examining the critical success factors, barriers, and facilitators to the implementation of an online supported self-management intervention in the NHS

I would like to invite you to take part in the IMPART study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. I am happy to go through the information sheet with you and answer any questions you have. I suggest this should take about 10 minutes.

Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to understand the implementation of an online toolkit to support relatives of people with bipolar depression and psychosis. The aim is to gain a detailed understanding of experiences, expectations, barriers, facilitators, successes and failures with the delivery and adoption of REACT. This information will be used to inform a national Implementation Plan for online interventions to support relatives in mental health services. It is hoped that your perspective will help in the future implementation of online interventions within the NHS.

Why have I been asked to participate?

You have been asked to consider participating because you are a relative receiving support from one of the participating NHS Trusts.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, you will be asked to sign a consent form. Even if you decide to take part then you do not have to answer all the questions and you can stop the interview at any time. You are free to withdraw from the interview at any time, without giving a reason. Withdrawal of data from the study will only be possible up to one month after the interview has been undertaken.

What will happen to me if I take part?

The interview will last around 45-60 minutes. You will be asked a series of questions that allow for exploration of your personal experiences of receiving support for you role in caring for someone with a mental health problem. We are interested in talking to you whether or not you have been offered any online support. Interviews will be conducted at a time and place that is convenient for you. The interviews will be audio-recorded. If you do not wish to be audio-recorded then written notes can be taken instead.

Will what I say in my interview be kept confidential?

All information will be kept confidential. Your interview will only be listened to in full by a transcriber within the research team. Following transcription, the interview will be anonymised and the audio recording destroyed. Following analysis to identify the key themes across data sources, the findings of the study will be presented in written papers and conference presentations. Anonymised quotes from the interviews may be used, but care will be taken that quotes cannot be attributable to any source.

What are the disadvantages of taking part?

The research team does not think that there are disadvantages to taking part although the interviews will require 45-60 minutes of your time.

What are the possible benefits of taking part?

The research team cannot promise that the study will help you but the information we gain from your interview will be used to help improve our knowledge and inform a national implementation plan for online interventions.

Who is organising the study?

The study is being carried out in collaboration between Lancaster University, University College London (UCL), The University of Liverpool and several NHS Trusts across the UK. Contact for further information

Who is funding the research?

The National Institute of Health Research (NHIR) has funded this three-year research project

Who has reviewed the study?

This study has been extensively peer reviewed, funded by the National Institute of Health Research, and approved by an NHS Research Ethics Committee responsible for ensuring that ethical considerations and issues are addressed in the conduct of research

What will be done with the information I give?

It will form the basis of the IMPART study and inform a national implementation plan for the REACT toolkit. The findings will also be published in academic journals and be presented at conferences.

What if there is a problem or who do I contact regarding the study?

If you have a concern about any aspect of this study, or you wish to gain further information, you should ask to speak to the researchers who will do their best to answer your questions:
[Researcher contact details]

Spectrum Centre for Mental Health Research
Division of Health Research, Lancaster University, Lancaster, LA1 4YG

Alternatively you can contact: **Rd. Fiona Lobban**, Co-Director, Spectrum Centre for Mental Health Research, School of Health and Medicine, Lancaster University, Lancaster, LA1 4YG.
Telephone: 01524 593756. **Email:** f.lobban@lancaster.ac.uk

If you would prefer to speak to someone outside of the research team then please contact the Associate Dean for Research at Lancaster University:

Professor Roger Pickup
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG
Tel: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the REACT team:

REACT Team
The Spectrum Centre for Mental Health Research
Faculty of Health and Medicine

(Department of Health Research)

Lancaster University
Lancaster
LA1 4YG
Tel: insert once have REACT mobile phone contract
Email: react@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Carers UK 0808 808 7777(UK)

NHS emergency services:
Call 999 (UK)

NHS for non-emergencies:
Call 111 (England)
Call 0845 46 47 (NHS Direct Wales)
Visit www.nidirect.gov.uk for Out of Hours GP contacts in your area (Northern Ireland)

Samaritans: call 08457 90 90 90 (UK)

Appendix 4C: Consent Form

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IMPART Study: Consent form for individual interviews

Please insert your initials in the boxes provided to indicate 'YES' to the following statements:

I have read and understood the information sheet and I have had the opportunity to ask questions	☐
I agree to the interview being audio-recorded and/or written notes being undertaken **(delete as appropriate)**	☐
I understand that I am free to not answer any questions during the interview and may stop the interview at any point	☐
I understand I will be able to withdraw my data from the study within one month after the interview has taken place	☐
I understand that my participation will be anonymous and any details that might identify me will not be included in reports or other publications produced from the study	☐
I understand that a transcriber will have access to the audio-recoding of the interview, for transcription purposes.	☐
I understand that data collected from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information	☐
I agree to have my transcribed anonymised interview data stored for 10 years by Lancaster University /University College London	☐
I agree to take part in the interview	☐

Name (PRINT): Signature:	Date:
Name of researcher taking consent: Signature:	Date:

If you would like a copy of the key themes to emerge from this study please indicate how you would prefer to receive a copy of this document, i.e. through email or by post (home or work address) and give your contact details.	I would like to receive a copy of the key themes Yes/No I would like to receive them by Email/Post Contact details:

Appendix 4D: Interview Topic Guide

Relatives Interview Topic Guide

Opening:

(**Establish rapport**) My name is [ ] and I am interested in understanding your experiences of being a relative of someone with a mental health problem, and specifically the kind of support you have received from the clinical team.

<u>IF USED REACT</u>

You have been chosen for interview because you have experience of using the REACT toolkit. I would like to ask you several questions regarding your background, experience and perspectives in relation to your use of the REACT toolkit, the ways the toolkit might be improved, what aspects of the toolkit worked well and any other comments you might want to make about the toolkit.

(Motivation) I hope to use your comments to understand ways to improve health services and support for people with mental health issues. It is hoped that this research will guide the development of a model aimed at improving the implementation of online support interventions.

(Time-line) I anticipate that the interview should take around 45-60 minutes. If you have less time available, please let me know and I will adjust the interview to suit you.

Questions

The interview will be conducted flexibly, using language familiar to the participant, and therefore specific questions are not pre-set. However, the following key topic areas will be explored:

- Experiences of supporting someone with a mental health problem (briefly for context only).

- Thoughts about current support available to relatives within the Trusts

- Knowledge, experience and views regarding the REACT toolkit

How they first heard about it / how easy it was to access / how easy to use? / what were barriers to use? / what helped use? / a walk-through of what happened from first hearing about REACT to now, exploring expectations, emotional reactions, thoughts.

What impact (if any) has REACT had on them / other family or friends?

What advice would they give to someone designing this toolkit?

Knowledge, experience and views regarding use of the internet in general – and specifically any other online interventions they are aware or have used in the NHS (or in other settings).

Their general views on the use of online interventions to deliver healthcare support.

IF NOT USED REACT

You have been chosen for interview because you are receiving support from the Early Intervention in XXXX Trust.

I would like to ask you some questions regarding the kind of support you have received. I am also interested in your views about online support and how this could be used to support relatives.

I hope to use your comments to understand ways to improve health services and support for people with mental health issues.

(Time-line) I anticipate that the interview should take around 45-60 minutes. If you have less time available, please let me know and I will adjust the interview to suit you.

Questions

The interview will be conducted flexibly, and therefore specific questions are not pre-set. However, the following key topic area will be explored

- Experiences of supporting someone with a mental health problem (briefly for context only).

- Thoughts about current support available to relatives within the Trusts.

- Are they aware of REACT? Have they received an email about REACT? If so, was there a decision made not to use REACT? (Explore this rationale).

- Knowledge, experience and views regarding online support.

Have they ever used anything online? / if not – why not? / How they first heard about it / how easy it was to access / how easy to use?/ what were barriers to use?/ what helped use?/ a walk-through of what happened from first hearing about an online resource to now, exploring expectations, emotional reactions, thoughts.

What impact (if any) has online support had on them / other family or friends?

What advice would they give to someone designing online support for relatives?

Knowledge, experience and views regarding use of the internet in general – and specifically any other online interventions they are aware or have used in the NHS (or in other settings).

General views on the use of online interventions to deliver healthcare support

Ending

Well it has been a pleasure to talk to you today, and your views are really helpful to our research. Is there anything that you would like to add or feel that we have not discussed and should?

I would like to thank you for your time, your comments will be very useful for my research and I will be in touch shortly with the emerging themes from the interviews. Do you have any questions?

I should have all the information I need, would it be ok to contact you on the number or email address provided if I need to clarify any points?

Thanks again and do not hesitate to contact me with any questions that you may have regarding the research.

Appendix 4E: Recruitment flyer

Version 1.0 12/12/2017

Invitation to share your views about REACT

We would like to invite you to share your views and experiences of being offered or using REACT because you are a family member or friend of someone who is receiving support from an NHS Trust that is participating in the IMPART study.

What is the IMPART study?

- IMPART stands for the **IMP**lementation of a **R**elatives' **T**oolkit. The study aims to understand how easy or difficult it is to access and use REACT (Relatives' Education and Coping Toolkit), and whether or not people find it useful.
- The information gathered will be used to inform a national Implementation Plan to improve the delivery of online support and resources for family and friends of people accessing mental health services.

What will I be asked to do if I decide to take part?

- You can take part in an informal interview with a member of the IMPART research team over the phone or in person, or a group discussion with up to 10 other relatives.
- You will be asked about your experience of receiving information and support while supporting someone with a mental health problem, and your experience of being offered REACT and whether you have found it useful. All information you share with us will be kept confidential.
- You will receive a £20 shopping voucher as a thank you for your participation and will be reimbursed for your travel expenses if you are required to travel.

How can I find out more?

If you think you might be interested and want to find out more, please contact [**RESEARCHER NAME**]:

☎ [**INSERT PHONE NUMBER**]

✉ [**INSERT EMAIL ADDRESS**]

🏠 [**INSERT UNIVERSITY ADDRESS**]

[INSERT RELATIVE'S NHS TRUST LOGO HERE]

Appendix 4F: REC approval letter

Health Research Authority

East of England - Cambridge South Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

26 January 2018

Miss Johanna Barraclough
Doctorate in Clinical Psychology Programme
Furness College, Lancaster University
Lancaster
LA1 4YT

Dear Miss Barraclough

Study title:	**Implementation of a relatives' toolkit (IMPART Study): Examining the critical success factors, barriers, and facilitators to the implementation of an online supported self-management intervention in the NHS**
REC reference:	**16/EE/0022**
Amendment number:	**3**
Amendment date:	**19 December 2017**
IRAS project ID:	**194741**

The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence on 12 January 2018.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Relative recruitment flyer 12122017V1.0.pdf]	1.0	12 December 2017
Interview schedules or topic guides for participants [Topic Guide Focus Groups Relatives v1.012122017.docx]	1.0	12 December 2017
Notice of Substantial Amendment (non-CTIMP) [Amendment 3_19.12.17.pdf]	3	19 December 2017
Other [Appendix 1 IMPART study protocol ver 1.212122017.docx]	1.2	12 December 2017
Other [Appendix 8 Relatives interview schedule12122017 v1.1.docx]	1.1	12 December 2017
Participant consent form [Consent Form Focus Groups Relatives v1.0 12122017.docx]	1.0	12 December 2017
Participant information sheet (PIS) [Information Sheet Focus Group Relatives V1.012122017 .docx]	1.01	12 December 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

16/EE/0022: Please quote this number on all correspondence

Yours sincerely

PP.

Dr Leslie Gelling Chair

E-mail: nrescommittee.eastofengland-cambridgesouth@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms XXXXX, XXXXX Partnership NHS Foundation Trust*
Miss Johanna Barraclough

East of England - Cambridge South Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 12 January 2018

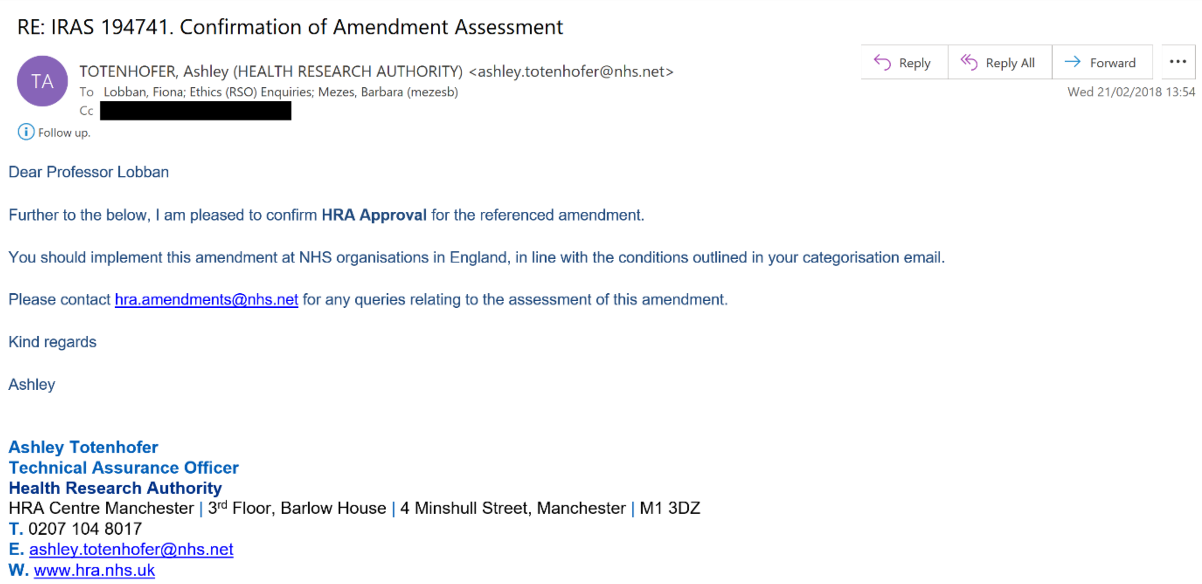
Committee Members:

Name	*Profession*	*Present*
Dr Leslie Gelling	(Chair) Reader in Research Ethics	Yes
Mr Phil Tempest	Compliance Manager	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Mr George R. Martin	REC Assistant (Minutes)

Appendix 4G: HRA confirmation of approval



RE: IRAS 194741. Confirmation of Amendment Assessment

TOTENHOFER, Ashley (HEALTH RESEARCH AUTHORITY) <ashley.totenhofer@nhs.net>
To Lobban, Fiona; Ethics (RSO) Enquiries; Mezes, Barbara (mezesb)
Cc [redacted]

Wed 21/02/2018 13:54

Dear Professor Lobban

Further to the below, I am pleased to confirm **HRA Approval** for the referenced amendment.

You should implement this amendment at NHS organisations in England, in line with the conditions outlined in your categorisation email.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Ashley

Ashley Totenhofer
Technical Assurance Officer
Health Research Authority
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