

Understanding and improving transitions of older people: a user and carer centred approach

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Published September 2012



This project is funded by
the Service Delivery and
Organisation Programme

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Conflicts of interest:

The authors have no financial or other competing interest that might have biased this work.

This report should be referenced as follows:

Ellins J, Glasby J, Tanner D, McIver S, Davidson D, Littlechild R, Snelling I, Miller R, Hall K, Spence K and the Care Transitions Project co-researchers. Understanding and improving transitions of older people: a user and carer centred approach. Final report. NIHR Service Delivery and Organisation programme; 2012.

Relationship statement:

This document is an output from a research project that was commissioned by the NIHR Service Delivery and Organisation (SDO) Programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. From January 2012, the NIHR SDO programme merged with the NIHR Health Services Research programme to establish the new NIHR Health Services and Delivery Research (NIHR HS&DR) programme. Should you have any queries please contact Hsdrinfo@southampton.ac.uk

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This report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and not necessarily those of the NHS, the NIHR or the Department of Health.

Criteria for inclusion

Reports are published if (1) they have resulted from work for the SDO programme including those submitted post the merge to the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors. The research in this report was commissioned by the SDO programme as project number 08/1809/228. The contractual start date was in November 2008. The final report began editorial review in November 2011 and was accepted for publication in September 2012. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The SDO editorial team have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report documentation. However, they do not accept liability for damages or losses arising from material published in this report.

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Glossary of terms/abbreviations

A&E	Accident and emergency
BME	Black and minority ethnic
GP	General Practice/Practitioner
LPA	Local partner agency
OD	Organisational development
PR	Participatory research
PCT	Primary Care Trust
SDO	Service Delivery and Organisation programme

Acknowledgements

The research team are grateful to the case study sites for agreeing to participate in this study, to the statutory and voluntary sector organisations that acted as our local partners, and to the members of our national advisory group. We would particularly like to thank the 22 older people who – as co-researchers – made a significant contribution to the research process and outcomes. Finally, we are grateful to all the older people who took the time to share their views with us, and helped us to understand the lived experience of care transitions.

Contributions of authors

Jo Ellins was the lead researcher and project manager, and is the guarantor for this study. She undertook the research in one of the case study sites and assisted in the implementation activities at the site. Jo also contributed to the design of the study, development of the proposal, development of the co-researcher training programme and interview tools, budgetary and data management, coordination of the national advisory group, analysis of the findings and writing and editing the report.

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Kelly Hall contributed to the evaluation of the participatory approach and writing the final report.

Katie Spence contributed to the evaluation of the participatory approach.

The *Care Transitions Project* co-researchers contributed to the design of the interview methodology and tools, participant interviews, data analysis and presentation of the findings at local feedback events.

Executive Summary

Background

Older people – especially those with complex and ongoing needs – often move across service boundaries. Poorly planned and coordinated transitions can be detrimental to older people's health and well-being, and are a source of major disagreement between service commissioners and providers. Despite positive changes following the 2001 National Service Framework for Older People, transition between services is still one of the most problematic areas of policy and practice.

The contribution that older people can make as co-researchers is increasingly recognised. Rather than being passive suppliers of information, as in traditional research approaches, co-researchers have a role in shaping the research agenda and co-producing its outcomes. This approach opens up the possibility for older people to explore and define their own experiences: doing research 'with', rather than research 'about'.

Aims

The aim of this study was not just to understand older people's experiences of care transitions, but also to conduct the research in a way that would help to embed the findings in health and social care policy and practice.

Specifically, it aimed to:

- Explore older people's experiences of moving across service boundaries, examining access to services, and information, advice and support needs
- Identify how the needs of particular groups of older people may differ from each other, and the different needs of service users and carers
- Investigate these issues over time, to illuminate how previous transitions impact on current and future needs
- Draw out policy and practice implications for the way in which services prepare and support older people and their carers for care transitions
- Support, and share the learning from, implementation of project findings in four health and social care communities.

Methods

This study was carried out in two phases across four case study sites in England. Each site focused on the transitional experiences of a different group of older people:

1. Who have dementia
2. From ethnic minority communities
3. Living in rural areas
4. Living in an area with a proportionally small older population.

Phase 1 (research) involved in-depth narrative interviews with older service users and carers; participants were followed up approximately six months after their initial interview to explore whether and how care needs following transition had changed and were met over time. In Phase 2 (implementation), the research team fed back the research outcomes to the four sites, and worked with key stakeholders to use the findings to reflect on and develop local practice.

In each site a group of older people were recruited as co-researchers, working with an academic researcher to plan and carry out the research as well as contributing to the implementation phase activities. A broader local infrastructure for the study was also established, with a statutory and voluntary sector lead partner agency in each area that worked with the research team to build and sustain local engagement. Partner agencies selected a specific transition to be the focus of the study in their area; this helped to establish local ownership from an early stage, and ensured that the research linked with existing local initiatives and priorities. Two transitions were selected: entry into and moving between dementia services (site 1) and going into and leaving hospital (sites 2-4). An evaluation of the participatory approach was also carried out involving qualitative interviews and focus groups with key stakeholders involved in the study.

Results

1. Research phase

This study explored the experiences of different groups of older people, in different locations and circumstances, during different types of health and social care transition. Despite this considerable variation in the topic of investigation, the needs, preferences and expectations which older people had in common were far greater than those on which they differed.

Experiences of transition were frequently accompanied by a sense of disorientation and feelings of fear, worry and uncertainty. Rather than being discrete events, as they are sometimes seen by service providers, transitions were often continuous so adaptation to new circumstances had

to be ongoing. In these situations, people sought to make sense of what was happening to them, in order to cope with and adjust to their experience. They wanted to be seen as a human being, rather than a problem to be solved. Even small gestures by providers to connect with somebody as a person could make a significant difference to their sense of dignity and their overall experience.

Good communication by service providers assisted sense-making activities and helped people to feel safe and connected in an otherwise 'foreign land'. However, many participants faced difficulties trying to access even basic information about their health and services, and notification and preparation for transitions such as discharge from hospital was generally poor. Experiences of stumbling across services, having to seek them out, or even in some cases needing to fight for them were common.

The importance of home and social support in older peoples' lives cannot be overstated. Participants often did not feel comfortable coming forward to seek help from formal services at an early stage, and often found it easier to ask for help from family and friends. Getting to know people in service provision roles over a period of time enabled older people to develop meaningful relationships, and make it more likely that support could be provided flexibly and responsively on an ongoing basis. But the reality for many fell short of this, and poor continuity in care and support arrangements was a frequently mentioned problem.

2. Implementation phase

The implementation phase commenced with local events to feedback the research findings to local services and stakeholders. Older people co-designed these events and read out extracts from participant interviews to illustrate key themes from the experiences shared during interviews. This had a powerful effect: rather than being treated as disaggregated data, services were able to see and connect with the findings as real-life experiences; this helped to generate momentum for change.

Stakeholders across the case study sites said that there were 'no surprises' in the research findings: the issues which the research identified had existed and been known about for many years. Because of this, a wish not to duplicate efforts and consideration of the difficult financial context, local stakeholders embedded implementation into existing work programmes and initiatives. While this approach felt justified, it conflated the findings with a much broader range of plans and activities, and this may have served to lose focus. The exception to this was in Manchester, where a project to guide the development of a person-centred single assessment process emerged from the findings and feedback event.

Engaging the statutory sector was essential to ensuring that change occurred, but this proved difficult at a time of substantial policy and organisational change. Furthermore, our approach did not produce the kind of instrumental data that local services may prefer and a challenge arose in

seeking to translate complex lived experiences into tangible service improvements. An important lesson from this study is that gathering experiences in the form of stories enhances their power and richness, but may demand even more careful and creative thinking to turn 'raw data' into concrete actions.

3. Evaluation of the participatory approach

The main motivation for co-researchers to participate in this study was the desire to improve services, often resulting from their own experiences as service users and carers. Co-researcher involvement was felt by all stakeholders to have had a positive impact on the study, especially in terms of data collection and local dissemination of findings. There was general agreement that having older researchers involved in the interviews put participants at ease and that it was helpful for the person interviewing to share some characteristics with the interviewee. Factors that helped the co-research model included time for academics and co-researchers to develop relationships and trust, and the provision of training and support.

Conclusion

Care transitions involve far more than a move across services or settings. Participants in this study experienced transitions on a number of different levels: 1) physical, including bodily changes as well as use of services; 2) psychological, with changes in their identity or sense of self; and 3) social, with changes in their relationships with partners, family and friends. These different transitions often happened simultaneously and if circumstances made coping difficult in one type of transition then it was likely to have an effect on others. Whilst the physical aspects of transition are often a priority for service providers, the importance of the psychological and social aspects was frequently overlooked.

The way older people are treated by professionals and staff has a considerable impact on their overall experience. Most of the suggestions participants made for improving services called for 'micro-changes' in the care environment and in interpersonal relationships. There was little suggestion that what was needed was new or different services; easier and earlier access to existing services emerged as a far greater priority. While these micro-changes may not cost large amounts of money, they do require committed and sustained effort to challenge existing ways of working that may be deeply ingrained in organisational and professional cultures.

1 Introduction

Despite a series of positive changes following the 2001 National Service Framework for Older People (1), research and inspection reports continue to reveal that transition between services is one of the most problematic areas of policy and practice (2). In particular, the evidence suggests that older people and their carers frequently experience (3-5):

- Poor communication between services
- Lack of adequate assessment and planning prior to transition
- Inadequate notice of/preparation for transition between services
- Inadequate consultation and involvement
- Over-reliance on informal support
- Inattention to the special needs of particularly vulnerable groups
- An increased risk of premature transition and/or transition to inappropriate care settings due to service pressures and inter-agency tensions.

While this seems to be particularly the case with regards to hospital admission, hospital discharge, intermediate care and entering a care home, the emerging evidence nevertheless suggests that *any* process of transition can be a negative experience if poorly coordinated. It is likely that transition poses a significant added difficulty to some groups of older people, particularly where they have complex and multiple needs which span traditional service boundaries.

The importance of smooth and supported transitions is underscored by recent government policy, emphasising a key role for health and social care providers in promoting independence and wellbeing in older age (6-8). This includes providing ongoing support to almost half of the older population who has one or more long term conditions (LTCs). A stratified delivery model for LTCs was introduced in 2004, which identifies three levels of care that a person might receive: support for self-management; care management for people who have a complex single need or multiple conditions; and case management for very high intensity users of unplanned secondary care (9). In thinking about service transitions, this model points to two key issues. First, transitions can be understood as moves between different levels care as well as between different care settings. Second, transitions from institutional to home settings should take account of the complexity of older people's needs, which may vary from low intensity self-care support to high intensity case management.

1.1 Previous research and key issues

This report has been produced by a team from the Health Services Management Centre (HSMC) and Institute for Applied Social Studies (IASS) at the University of Birmingham. Over time, members of the research team have been involved in the national evaluation of intermediate care (10) and Department of Health-funded research into the rate and causes of delayed transfers of care for older people (3). From this and other research, we believed that the problems with transition for older people were already well documented. For example, studies on older people's experiences of hospital discharge report remarkably similar findings over more than thirty years (3;4).

Given this, the aim of this study was not just to answer the questions posed in the SDO commissioning brief, but also to conduct the proposed research in a way that helped to embed findings in policy and practice. Therefore, the initial data gathering phase reported below was not an end in itself, but the beginning of a process designed to facilitate the application of findings into practice in older people's services.

Overall, our specific objectives were to:

- Explore older people's experiences of care transitions, identifying positive and negative experiences, information and advice needs, access to services and needs for ongoing support
- Identify how the needs of particular groups of older people may differ from each other, and the different needs of service users and carers
- Investigate these issues over time, to illuminate how previous transitions impact on current and future needs
- Draw out policy and practice implications for the way in which services prepare and support older people and their carers for transition between services and settings
- Support, and share the learning from, the implementation of project findings in four health and social care communities.

To address these issues, the research team was adamant that only an approach which built upon the active involvement of older people themselves would be sufficient to do justice to the complexities of older people's experiences and provide a sufficiently detailed and nuanced evidence base with which to try to influence change at local level (see below and Chapters 3 and 8 for further discussion).

1.2 The importance of participation

It is increasingly recognised that older people must be at the centre of efforts to improve the quality and responsiveness of services for their use. A programme of research about the lives of older people carried out in the

early 2000s concluded that, 'there is still a mismatch between what older people want and what policy and practice are delivering' (11). In view of this, it was recommended that services are 'worked up' from priorities and needs as defined by older people, through direct involvement in research and service planning, design and delivery. This recommendation has been echoed in government policy (12), good practice guides (13) and academic literature (14). It is also underpinned by wider trends in public policy to move away from paternalistic models of service delivery and give service users a greater say in issues that affect their lives (15).

Within a research context, the contribution that older people can make as co-researchers is increasingly recognised (16-18). Whereas traditional research methods typically involve participants as passive suppliers of information, participatory research calls for a collaborative approach in which participants can shape the research agenda and co-produce its outcomes. Such collaboration opens up the possibility for individuals and groups to explore and define their own experiences: a case of doing research with, rather than research about. The findings from participatory research studies suggest that this approach can produce data that are grounded in specific local contexts and experiences, thereby providing richer and more authentic insights than non-participatory methods. This kind of 'living knowledge', it has been argued, is practical, useful and can be more readily translated into action (19); it is in this sense that participatory research is often described as an action-oriented approach. The production of 'actionable' data and emphasis on local ownership of the research processes makes participatory methods particularly suitable where the aim is improve practice.

Participatory approaches call for an opening up of the research process to service users and their carers. While this challenges the power differential inherent in established research traditions, additional barriers may need to be addressed in order to achieve a genuine collaboration and avoid tokenism (17). Previous studies indicate that training and support is essential so that older people can confidently participate in research activities and use their findings to influence policy and practice. Moreover, additional support for provider organisations may be necessary to facilitate processes of change and maximise impact (20). As this suggests, the methodology of participatory research and techniques of organisational development are closely aligned (see Chapter 3 for further discussion).

1.3 Report structure

After this introduction, Chapter 2 provides a backdrop to the study via a review of the literature and key concepts. While the problems of fragmented and poorly coordinated care are well documented, there have been fewer studies exploring older people's perceptions of such issues, and this chapter draws on insights from the broader psychological, nursing and management literature in order to develop our framework for understanding and

analysing transition. After this, Chapter 3 sets out our methodology, including details of the co-research model and our dual emphasis on both research and implementation. This includes a discussion of the methodological literature on action-oriented and participatory research, which underpinned key aspects of our approach. Chapters 4 to 7 report the main findings from the four case study sites, each of which worked with a different group of older people. Chapter 8 summarises the main cross-cutting themes from the research and implementation phases, while the findings of the evaluation of the participatory approach are shared in Chapter 9. Limitations of our approach and recommendations for health and social care practice can be found in Chapter 10. Throughout, the study has drawn heavily on the lived experience of local older people, and the main body of the report includes multiple quotes from our interviews to enable older people's perceptions of the issues at stake to shine through and lead our subsequent analysis.

2 Understanding transitions

Research into the experiences of older people moving between services has tended to focus on the physical changes that take place rather than the psychological and/or social changes that these transitions may also involve. Even where other dimensions of change are studied, these are usually from a service rather than an older person's perspective. In contrast, this study argues for a broader understanding of the concept of transition and one that draws on the contributions of older people themselves. Using examples from research into patients' experiences of hospital discharge and older people moving into residential care, this chapter proposes a research framework that incorporates three dimensions of change that relate to the process of transition, and six different perspectives, from individual to system wide, that are involved in service delivery.

In particular, the chapter:

- Explores some key concepts and frameworks from the transitions literature
- Examines findings from research on two examples of service transition – arguing that by starting from the older person's experience of transition and then examining the implications for services, this may help to improve service re-design
- Emphasises the importance of focusing on three aspects of transition: physical, psychological and social
- Proposes an analytical framework which combines the features of transition discussed, namely: 1) the different perspectives which have implications for the levels of activity needed to promote joint working with 2) the different stages that comprise transitional journeys and 3) physical, psychological and social dimensions that have implications for the types of interventions required to help people cope with these transitions.

2.1 *Initial definitions*

The term 'transition' is used in natural science disciplines (for example, geography, metallurgy), as well as in several branches of social science including anthropology, psychology and sociology. It also has practical applications in areas such as nursing and management, where it refers to the human response to change. Different types of human transitions have been studied including developmental or life stage transitions, situational or role transitions, health and illness related transitions and environmentally created transitions such as those instigated by organisational change. Most

writers point out that the study of transitions is more than a focus on the human experience of change and that the process of transition involves similar features whatever the situation. In particular, the work of anthropologist Arnold van Gennep has been influential (21). He described the socio-cultural rites involved in the different stages of moving from one social status to another:

1. Pre-liminal rites (rites of separation) in which the individual is removed from their social situation
2. Liminal rites (rites of transition) in which the individual is in limbo
3. Post-liminal rites (rites of incorporation) in which the individual takes up their new social status.

Building on this approach, Bridges identified a three-point transition framework to explain the shape of personal change and the inner process of transition: endings (letting go/acknowledging the end of something); the neutral zone (a gap in continuity, limbo); and new beginnings (emotional readiness to do things in a new way) (22).

Typically, the broader literature suggests that all transitions have common features or stages, including some sort of antecedent, a particular trigger, the transition experience itself and subsequent consequences or new beginnings. They are usually social and psychological as well as physical, and similar processes and features seem to occur whether it is individuals working through change and transition, groups of staff, or whole organisations (23).

2.2 Transitions in health and social care

In health and social care, transition has been studied primarily within nursing where it has been identified as a central concept (24). A review of the nursing literature on transitions carried out by Kralik and colleagues (25) identifies a frequently cited definition given by Chick and Meleis (26):

A passage from one life phase, condition, or status to another...
Transition refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness, perception and patterns and response.

For Meleis and colleagues there are five elements of transition experiences: awareness, engagement, change and difference, time span and critical points (27). However, in their review of the nursing literature on transition, Kralik and colleagues point to a lack of consensus among researchers about the nature of the process (25). There is disagreement about whether transition processes have a definite beginning and end and whether they are linear or cyclical. Studies have reached different conclusions, suggesting

that the nature of the process might be dependent on the circumstances involved. For example in diagnoses of cancer, transition may last for several years and appears to follow a pathway (although this may be a spiral one) (28). In other chronic conditions the path may be more convoluted with forward and backward movement (29). In particular, the case studies included in the theoretical analysis conducted by Meleis and colleagues led them to conclude that transitions were often multiple and complex. They write (27):

In light of the results of these studies, our analyses of the nature of transitions suggest that nurses need to consider the patterns of all significant transitions in an individual or family's life rather than focusing only on one specific type of transition.

All of this suggests that, although the process of transition may have common features, the ordering or inclusion of each feature may vary.

An important part of Meleis and colleagues' model (and one that is not surprising given its nursing origin) is the identification of conditions that facilitate or inhibit progress toward 'achieving a healthy transition'. These include personal conditions such as cultural beliefs and socio-economic status, community conditions such as local resources, and societal conditions such as marginalisation. A number of related process and outcome indicators of a 'healthy transition' are identified which are summarised below (see Figure 1).

Figure 1. Transition process and outcome indicators

- Feeling connected
- Interacting
- Location and being situated
- Developing confidence and coping
- Mastery of new skills

Source: Meleis and colleagues (2000)

The literature on transition summarised above has some parallels with sociological studies of chronic illness. Bury's research into the experiences of people with rheumatoid arthritis, for example, highlights the way in which chronic illness disrupts the structures of everyday life, having an impact on individuals, their families and wider social networks (30). This 'biographical disruption' includes three kinds of disturbances: physical (pain and stiffness), psychological (concept of self) and social (mobilisations of resources). Bury's research was significant in drawing attention to the way in which medicine (and similar sources of expertise) are used by lay people as a resource in times of pain and suffering, but this can also be limiting in

their search for meaning. Similar sociological studies of lay experience of illness make clear the difficulties that health professionals face in understanding the perspective of users and carers. In her research on patient-doctor communication in the management of Parkinson's disease for example, Pinder found that the moment of diagnosis was very different for each party (31). For patients, her study confirmed similar research on diagnosis which found it to be 'biographically shattering'; it was 'a time of utter turmoil for many patients'. For GPs on the other hand, it was often a 'eureka' moment when 'everything fell into place' and thus the experience was frequently a relief for them.

The above studies begin to highlight the gap in understanding that can exist between patients and health professionals, which is brought about by their very different experiences of the events taking place. Patients undergoing transitions are experiencing disruption in one or more areas of their lives and may feel they are living through a time of chaos and confusion. Professionals on the other hand are going about their daily routine in a familiar place.

In sum, the literature on transition in health and social care has two main directions:

1. It identifies the process of transition and the factors that are likely to have an influence
2. It suggests what a 'healthy' transition might include and how this can be measured.

However, sociological research on differences between lay and professional perspectives illustrate the importance of finding out lay experiences and definitions of a 'healthy' transition before attempting to design service solutions. With a few exceptions (32), the literature on transitions has taken a predominantly service provider focus.

In contrast, studies of older people suggest that they endeavour to preserve goals, values and relationships and try hard to adapt to disruptive situations. When faced with loss and change, they employ cognitive coping mechanisms, as well as practical strategies (33;34). Moreover, it seems that cognitive and emotional coping mechanisms become more important when situations cannot be controlled by other means (35). For example, there is a growing body of work on the identity preservation strategies employed by older people with dementia (36-39). With this in mind, the next section looks in more detail at service users' experiences of two types of transitions in care.

2.3 Service users' experiences of movement between services

One of the most frequently researched areas relating to health care concerns the views and experiences of people who have undergone

discharge from hospital (4), although very few studies focus on the transitional experience of patients in an emotional/psychological sense. One of the exceptions is Kydd (40) who makes use of Bridges' (22) work on transition. As described above, in Bridges' model has three stages: an ending; a period of confusion which can lead to high anxiety levels; and a new beginning. As Kydd states:

Older people classed as delayed discharges were in the second stage of 'a period of confusion and distress' and were anxious.

Anxiety and stress are closely allied and are known to have a deleterious effect on an individual's health. Kydd also highlights the poor availability of information about services, lack of involvement in planning transitions and moves between services, the importance of staff attitudes and personal relationships between staff and patients. Patients tended not to develop friendships with one another because they knew they were moving on, all of which could result in isolation and loneliness for the older person unless their family supported them. These findings are repeated in other studies of hospital discharge, with common themes including a lack of involvement in planning transition from hospital to community, inadequate notice, lack of information and significant anxiety (4). A further theme from this literature is that service providers are not considering the psychological and social aspects of transition. For example, in failing to involve patients in planning transition from hospital, or in not providing them with sufficient information, the needs of someone experiencing a period of confusion are not being met.

A second common example from the health and social care literature involves research into older people's experiences of being admitted to care homes. This demonstrates similar themes (particularly about lack of involvement in decisions), but in addition focuses on the social circumstances and needs of patients and their families. Thus, a study based on interviews with older people recently discharged from hospital to a care home highlighted the need to distinguish between older people's feelings about loss of their home, the process of moving and their new life in the care home. Older people might be satisfied with one aspect but unhappy about another (41). A major finding of this research was that the older people did not see themselves as having any choice or control over care decisions:

Among these individual stories, however, there was one theme which remained constant: the passivity of older people in the process of moving. They did not expect support from staff, and their coping strategies centred mainly on stoicism.

Evidence suggests that older people adjust to living in care homes by strategies such as: passive acceptance (the major approach); making the best of available choices (focusing on aspects they can still control); and reframing (e.g. positive comparisons with others) (42). According to Nolan and colleagues (43) the move is more likely to be regarded as a positive

choice if four features are present (see Figure 2). In a later study, carers' experiences of care home admission were explored (44). Above all, carers often felt that they had little choice in the decision about nursing home admission, and this was particularly the case where an older person had been transferred directly from hospital.

Figure 2. Factors contributing to a positive choice of care home

- **Anticipation:** extent to which prior thought and discussion had been given to the placement
- **Participation:** extent to which the older person and carers had participated in decision-making process
- **Information:** quality of information and advice
- **Exploration:** of alternatives, emotional responses

Source: Nolan and colleagues, 1996

Studies have also found that, after admission, care staff did not engage sufficiently with family carers in developing care plans (45; 46). Carers were also sometimes blocked from contributing to relatives' care in the way they wished. There was a lack of attention to carers' own needs such as their emotional needs following the transition, particularly concerning feelings of guilt, loneliness and regret (44).

In sum, the literature on older people's experiences of transition into a care home identifies a similar lack of understanding of psychological needs and in addition highlights a failure to meet social needs, particularly those of carers and family. Yet interventions designed to improve care for older people leaving hospital or moving into care homes do not necessarily seem to address these issues. For example, there have been a series of policies in recent years designed to promote care closer to home, intermediate care and reablement. These are often based on the recognition that hospital is an inappropriate place for older people to make longer-term decisions about their needs and that some sort of 'half-way house' is needed to provide the necessary time and space. However intermediate care and reablement schemes located within care homes can lead to new forms of institutionalisation in which 'adaptation to the norms of the institutional setting was almost as important a concept as the promotion of independence' (47). This draws attention to the fact that unless providers gain a better understanding of the transition experiences of service users and carers, new forms of care may be in danger of replicating the mistakes of existing approaches.

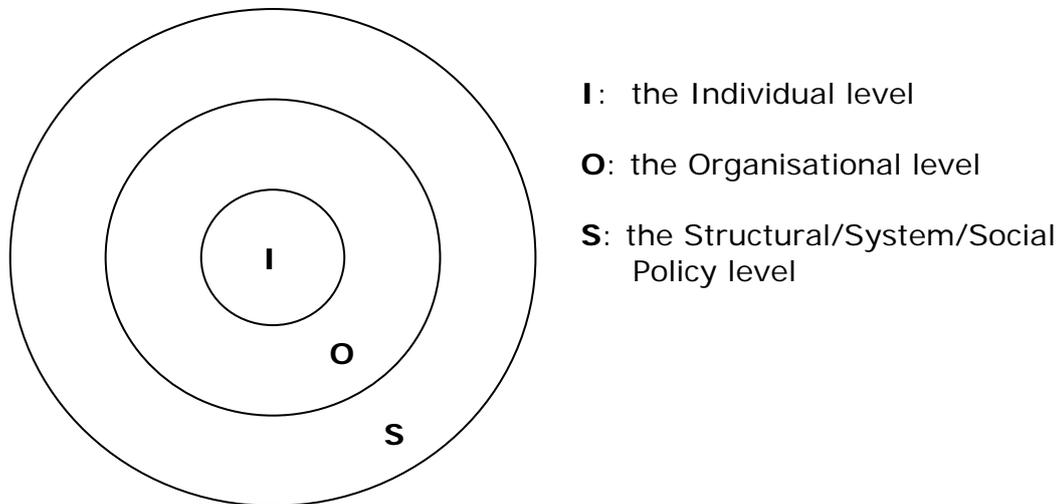
2.4 Towards a new framework

Reflecting on insights from the transitions literature and from research into service users' experiences of moving between services, three main themes emerge:

- Transitions take place over time and seem to follow a series of stages, although these can vary depending on the context. There is usually a before or antecedent stage, a significant event or trigger, the transition itself and an after stage when the consequences of the change create a new state.
- Transition can be a physical, psychological and social process for older people, but the research evidence suggests that the latter two dimensions may be neglected by service providers.
- Definitions of what makes a 'healthy' transition and service solutions to facilitate this are usually from a professional/service rather than an older person's perspective.

The transitions literature has important implications for anyone aiming to examine and improve the experiences of older people moving between health and social care services. However an additional insight comes from the broader literature on partnership working between health and social care. Reviewing the evidence around older people and hospital discharge, Glasby (4) has identified the need for health and social care to work together at a number of different inter-connected levels (see Figure 3). Thus, the contribution of individuals (I), although significant, takes place within a local organisational context (O), which itself is influenced by structural barriers (S) to improved joint working. Similarly, structural barriers derive at least in part from certain organisational features associated with particular types of health and social care agency and, ultimately, from the individual practitioners working within the organisations concerned. Building on this analysis, any service response to the difficulties older people may experience during service transitions may require coordinated action at a range of different levels if it is to be successful.

Figure 3. Different levels of partnership working



Source: Glasby (2003)

When applied to the context of transitions in care, this framework has similarities to the socio-ecological framework used by Graham and colleagues in their study of the transitional care needs of vulnerable older people in the United States (32). This includes five levels of: 1) the individual; 2) the interpersonal; 3) the organisational; 4) the community environment; and 5) policy. The researchers used this framework to assist in their examination of how the social environment affected people's experiences and behaviours during care transitions. This has implications for the development of a conceptual framework suitable for the UK public sector context, both in terms of analysing the social environment that affects the experiences of older people, and in identifying poor quality care that may require interventions which are coordinated across different organisations.

Building on these observations, this study proposes a new analytical framework that seeks to combine different perspectives and levels of activity with different stages of the transition process and with consideration of the physical, psychological and social aspects of transition (Figure 4). The study tries to do this by considering different levels of activity and perspective down one side of the framework (from individual service users and their families through to the whole organisation and the whole system) and different stages of the transition journey across the top (from antecedents to consequences).

Figure 4. Conceptual framework for the project

Systemic Levels of Analysis	Antecedents	Trigger	Processes			Consequences
			Entry	Throughput	Exit	
Individual						
Families and carers						
Community						
Services and staff						
Organisation						
System wide including: policy and commissioning						

3 Methodology

This study had two primary aims: 1) to understand the experiences of older people who had recently undergone a transition in care; and 2) to support the use of the research findings to identify and implement changes in local policy and practice. It was designed and implemented in two phases, carried out in four geographically distinct case study sites over a period of 35 months. Phase 1 involved in-depth qualitative interviews with older service users and carers, exploring their experiences of transition, identifying support needs and gathering suggestions for how local services could be improved. A longitudinal approach was employed, with participants followed up approximately six months after initial interview to explore whether and how care needs following transition changed and were met over time. In Phase 2, the research team fed back findings to the four sites, and worked with key stakeholders to reflect on and develop local practice. These are referred to as the 'research' and 'implementation' phases respectively.

In each site a group of older people were recruited as co-researchers to work alongside an academic researcher to plan and carry out the research in their area as well as contributing to the activities of the implementation phase. A broader local infrastructure for the study was also established. A statutory and voluntary sector organisation acted as project partners in each area, and worked closely with researchers to build engagement across the local health, social care and voluntary sector community. These are henceforth referred to as local partner agencies (LPAs). Voluntary sector LPAs also played a vital role in facilitating the co-research model, especially in terms of the recruitment and training of co-researchers, and the identification of participants. All of these roles are described in more detail below.

3.1 Study design

In this section, we provide an overview of the literatures and methodologies that informed our approach across the research and implementation phases.

3.1.1 Action and research

Most traditional research – whether positivist or interpretive – commonly employs a deductive approach: drawing on existing theory and knowledge to form hypotheses to guide empirical enquiry, and aiming to generate knowledge without altering the context and behaviours being studied (48). In so doing, it privileges 'knowing through *thinking* over knowing through *doing*' (49). Over the past century, developments in research methodologies have challenged traditional theory and method. Central to the beliefs

underpinning some of the challenges is the concept of 'reflexive action' (50), which brought together researchers and participants in a dialogue to expand knowledge and facilitate joint problem solving.

Under these influences, the balance of power between researcher and participant has shifted as greater emphasis was placed on empowering people to 'influence decision-making for their own aspirations' (49). Participants were no longer seen as passive suppliers of information, but instead as active co-producers of explanations and actions. A consequence of these shifts was the move from deductive to inductive approaches, involving iterative stages of data collection, analysis and theorising (51).

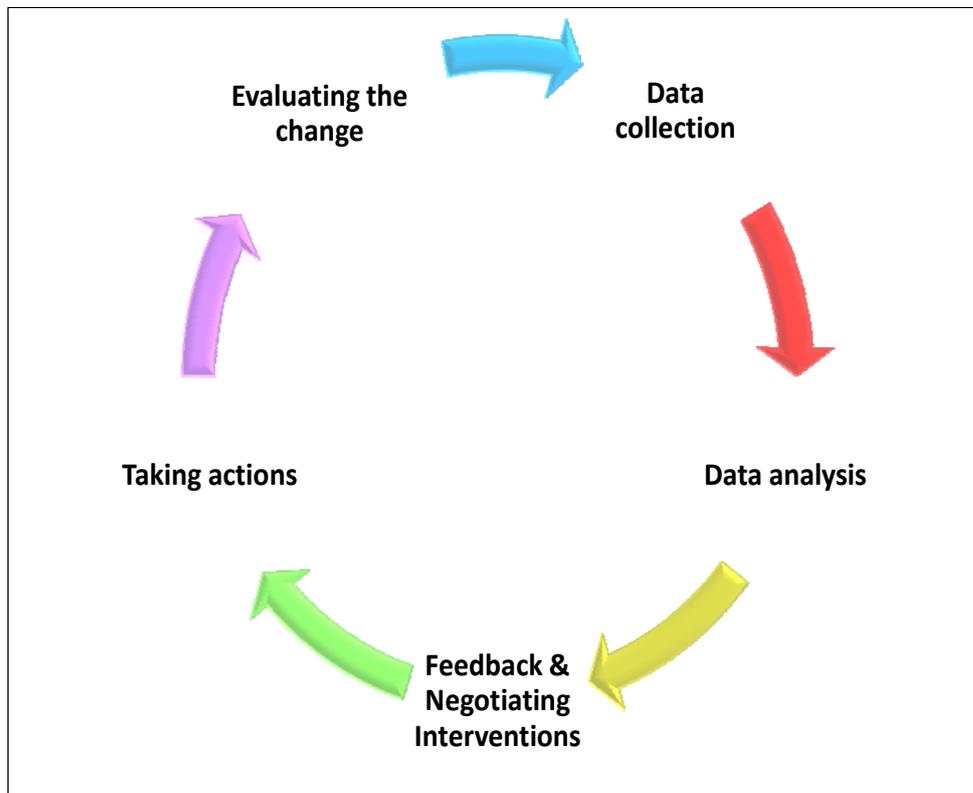
One approach that encompasses these paradigm shifts is action research, which Whitehead and McNiff refer to as a form of 'real-life theorizing' (52). While there are different types of action research, Reason and Bradbury (49) suggest that a common set of principles exist. Action research:

- Is a set of practices that respond to everyday challenges in organisations and societies
- Is concerned with engagement, collaboration and developmental dialogue between researcher and participants
- Values plurality and diversity in generating knowledge and understanding
- Is values-oriented inasmuch as it seeks to increase the well-being of those involved
- Is a living and emergent process such that outcomes cannot be predetermined.

In many respects, action research shares similarities with an organisational development approach (Figure 5), in which data collection (research) is but the first stage in a larger cyclical process that includes the negotiation, implementation and evaluation of change (53).

Given the applied nature of our research questions, the principles of action research and organisational development provided a useful basis for the study design. However, this still required the team to address the detailed research methods and consider how power relationships between the different stakeholders involved would be addressed. To inform our approach we again looked to action research. Hart and Bond (54) identify four distinct types of action research: organisational, professionalising, empowering and empowerment. They suggest that these four types can be differentiated on the basis of three criteria – the educative base, problem focus and improvement and involvement. This in turn informs the research relationship and degree of collaboration, as shown in Table 1 below.

Figure 5. The organisational development cycle



Source: Kolb and Frohman (1970)

The empowerment type of action research most fully reflected the values held by the project team and was capable of informing practices during both the research and implementation phases. However the need to address service improvement necessitated incorporating elements of the organisational type. This meant recognising and addressing the fundamental tensions between these two types of action research, one of which is organisationally led and focused, while the other encourages attention to user control and empowerment. Drawing on Brown's (55) ideas about organising the interfaces between researchers and the social systems they study, we identified a number of tensions (e.g. cultural factors, formal structures and technological processes) that needed addressing in the research design. In particular, it was essential to consider the relationship between different elements of the project, including the research and implementation stages, and the involvement of different local stakeholders (e.g. co-researchers, statutory agencies, voluntary sector organisations). Three mechanisms for articulating and working through these tensions were used: Local Advisory Groups, All Sites Days (both discussed in 3.2.2 below) and regular research team meetings.

Table 1. Four types of action research

Distinguishing criterion	Experimental	Organisational	Professionalising	Empowering
Educative base	Re-education Enhancing social science administrative control and social change towards consensus Researcher focused	Re-education or training Enhancing managerial control and organisational change toward consensus Managerial bias/client focused	Reflective practice Enhancing professional control and individuals' ability to control work situation Practitioner-focused	Consciousness raising Enhancing user-control and shifting balance of power; structural change towards pluralism User/practitioner focused
Problem focus	Problem emerges from the interaction of social science theory and social problems Success defined in terms of social science	Problem defined by most powerful group; some negotiation with workers Success defined by sponsors	Problem defined by professional group; some negotiation with users Contested, professionally determined definitions of success	Emerging and negotiated definition of problem by less powerful group(s) Competing definitions of success accepted and expected
Improvement and involvement	Towards controlled outcome and consensual definition of improvement	Towards tangible outcome and consensual definition of improvement	Towards improvement in practice defined by professionals and on behalf of users	Towards negotiated outcomes and pluralist definitions of improvement; account taken of vested interests
Research relationship, degree of collaboration	Experimenter/ Respondents Outside researcher as expert/research funding Differentiated roles	Consultant researcher, respondent, participant Client pays (and calls the tune) an outside consultant Differentiated roles	Practitioner or researcher Outside resources and/or internally generated Merged role	Co-researchers or co-change agents Outside resources and or internally generated Shared roles

Source: adapted from Hart and Bond (2000)

3.1.2 Older people as co-researchers

There is a growing body of literature about the engagement of service users (56-58) and carers (59;60) in research. Whilst there are now a number of accounts of older people's involvement in research with recommendations for good practice (61-63), there is little about the experiences of older people from black and minority ethnic (BME) groups and older people with dementia, two of our four key groups in this study. To date, we have found no publications that contain accounts of people with dementia recruited as co-researchers, although a number of research studies have challenged the assumption that the voices of older people with dementia cannot be heard in research (64-66).

Studies that have recruited older people as co-researchers identify attributes of warmth and the ability to communicate and empathise with the interviewees on the basis of shared experiences as beneficial to the research process (67). Other studies (59;68) report that older people are likely to feel more relaxed and at ease with a peer interviewer, thus ensuring richer, fuller data. Nevertheless, the recruitment of co-researchers can itself be a contentious issue (57). It involves debates about whether people are or should be representative; whether their identity as an older person is more important than their experiences as, for example, a woman, a disabled person, or someone from an ethnic minority group; and whether, as Ray points out, 'given the diversity of ageing, it is erroneous to assume a shared perspective' (14).

Warren and Cooke (61), suggest the value in older people planning and preparing for interviews is that they are more likely to know what to ask if they have had similar experiences to the interviewees. If older people are involved in the analysis of the data that they have collected, they can make sense of the findings using their own perspectives, which is more likely to ensure that the interpretation is accurate and relevant. Reflections from older people who have been recruited as co-researchers suggest that they are most often motivated to take on this role because of their desire to 'make a difference' having experienced poor quality services themselves (17;68). By being part of the research process including the dissemination of findings to service providers, older people are more likely to feel that findings will have an impact (58;69).

In contrast to these positive experiences, other studies have reported some drawbacks that stem from older co-researchers having had similar experiences to the people whom they are interviewing. Some accounts of service users as co-researchers talk about the 'emotional burden' which they feel from listening to the experiences of others and the responsibility they feel for having taken people back to distressing experiences (58). Some interviewees may assume that because they share similar assumptions and experiences with the interviewer they therefore can be less explicit in their accounts of what happened to them. Reflections from co-researchers show that a common anxiety is the tension between using

self-disclosure to facilitate mutual understanding and help interviewees to open up versus revealing too much of their own experiences (59). For some older people, embarrassment may be a factor and they may not want to be interviewed by someone who they think they may encounter elsewhere (58).

In considering the benefits and drawbacks of involving older people as co-researchers, there are a number of factors identified in the literature that are likely to add to the effectiveness of the participatory model. These factors present a challenge in their implementation because many seek to address the fundamental power imbalance that exists between academic researchers and lay co-researchers. Academics writing about their experiences of working with co-researchers identify that an acknowledgement of power differentials and a willingness to share their professional power are fundamental to establishing a successful relationship between the two parties (70;71). Schneider (71), writing about a participatory research project involving people diagnosed with schizophrenia, reflected on the dilemmas of being too directive versus letting the research project drift from its purpose:

I learned to let go of my need to be in control and to appreciate the unfolding of the process as the group members learned to take more control and direct this unfolding.

Whilst Schneider, with no training or expertise in mental health issues, could provide the 'research scaffolding', the co-researchers used their own experiences to develop the role of 'content experts'.

Many studies conclude that involving service user researchers from an early stage is the most effective way of ensuring involvement is meaningful (62;68). Not only do they have greater understanding and influence over the research process, but if the research study can be linked to decisions about changes in service provision, they are also more likely to be able to hold the service providers to account (58). However, Doyle and Timonen (69), found in a community-based participatory research project with older people in Dublin that the 'main priority [of the older people] was not to have extensive involvement of all aspects of the research but instead the translation of the research results into actions.' They conclude:

It is important to question the "gold standard" of participatory research, whereby high levels of involvement of older people in all aspects of the research are seen as preferable. We must question whether this is a standard that has been articulated by academic researchers, or older people themselves.

Good training and support for co-researchers is a key factor for successful involvement (68;72). Ensuring that researchers are well prepared in advance adds to their confidence and sense of value and worth (61;68). Time spent in debriefing is also likely to avoid the emotional reaction that some co-researchers refer to following intensive interviews. For Reed and

colleagues, the purpose of co-researcher involvement was to bring a 'unique contribution to the research process' (73). In light of this, they warned that:

It was a constant challenge to do this [train co-researchers] in ways that avoided turning them into (semi) professional researchers.

Cornes and colleagues (18), in their account of involving older people as researchers in the review of the National Service Framework for Older People, warn against the definition of involvement as purely encompassing the traditional research tasks. They remind us that:

In reality many more skills and competencies come into play, especially those rooted in team-building, communications and project management.

In their experience, the behaviour and spontaneous actions of the older co-researchers created a relaxed atmosphere that encouraged the participants to contribute more fully. Nevertheless, researchers who have taken these responsibilities to co-researchers seriously point out that funders should not underestimate the additional time and resources which such an approach requires (61).

There are examples of older people who have taken part in research becoming part of a more sustainable research group (17;62). Older People Researching Social Issues (OPRSI) is one such group which began as a group of older people who undertook a research methods course at the University of Lancaster and subsequently formed a co-operative consortium researching older people's issues (62). Such sustainability is rare and it is more likely that groups dissipate after the research project has ended if further funding is not forthcoming.

To summarise, the involvement of co-researchers in research projects can pose a number of tensions and recruiting co-researchers will not, on its own, ensure a positive outcome. The effectiveness of their involvement rests in part on the flexibility of academic researchers to manage the sometimes differing, and potentially conflicting, objectives of different stakeholders in the research process. Two key imperatives advocated by Dewar (17) are critical: 1) work with older people to explore what type of partnership they want; and 2) consider techniques and approaches to involvement that would promote equal partnerships. In preparing to work with older people as co-researchers in this study, we therefore kept to the fore Cowdell's (65) conclusion from a literature review of the preservation of personhood in dementia research:

Whilst guidance is available, the key element that enables effective data collection, regardless of espoused style, is the personal manner and approach of the individual interviewer.

3.2 Methods

3.2.1 Selection of case study groups, sites and transitions

Our literature review identified a sizeable body of research exploring older people's experiences of care transitions. However, the majority of studies focused on the experiences of older people in general with very little attention paid to particular groups whose needs might be expected to be different or more complex. Two such groups include older people from BME communities and older people with dementia (3). Locality may also have an influence on experiences. Research has shown that the delivery of services to older people in rural areas is particularly problematic; there is also evidence that service needs may be more fully met in areas where older people comprise a relatively large proportion of the overall population (so-called naturally occurring retirement communities) (74).

With these insights in mind, four groups of older people were selected as the focus for the research:

1. Older people who have dementia
2. Older people from BME communities
3. Older people living in rural areas
4. Older people living in areas with a proportionally small older population.

For each of these groups, a geographical area was chosen in which to carry out the research (henceforth referred to as the case study sites). For groups 2–4, information supplied by the Office for National Statistics was used to identify areas fitting the required profile from which a short-list was drawn. The final selection of these case study sites was made collectively by the research team, based on practical and methodological considerations.

In the case of group 1, our primary concern was to identify an area where we could work closely with a voluntary sector organisation which had significant experience of supporting the involvement of older people with dementia that we could draw on and learn from. This was felt to be particularly important in relation to working with older people with dementia as co-researchers. Consequently, selection of this case study site was based on existing links between members of the research team and a local branch of The Alzheimer's Society. While the branch in question covered both South Birmingham and Solihull, Solihull was chosen as the case study site because it offered the opportunity to explore transitions in one of the few areas in England that had an integrated care trust.

Following initial discussions with sites, it was agreed that the selection of a single type of transition would be of practical value in terms of recruiting participants, and identifying and engaging relevant agencies in the implementation stage. The selection of a transition type was typically

undertaken by the two LPAs in each site, sometimes following wider discussion with other local agencies. This approach was not only important in terms of establishing local ownership of the study from an early stage, but also helped to ensure that the research linked with and added value to existing local activities and priorities. The key characteristics of the case study sites are displayed in Table 2.

Table 2. Case study site characteristics

Older persons group	Case study area	Transition
Older people with dementia	Solihull	Entry into and moving between dementia services
Older people from BME communities	Leicester and inner Leicestershire	Going into and leaving hospital
Older people in rural areas	Gloucestershire	Going into and leaving hospital
Older people living in an area with a proportionally small older population	Manchester City	Going into and leaving hospital

3.2.2 Building a local infrastructure

Every process of change has three overall iterations: getting started, making progress and institutionalising, e.g. implementing and disseminating (75). Each of these phases has some simple needs to be satisfied in the work process for projects to succeed. The first and most important task is to establish an infrastructure for the programme as a whole, for each phase and for the transitions between phases. Without this infrastructure, projects are unlikely to succeed or develop with any coherence (76).

Getting started

Each case study site was allocated a research lead and an organisational development (OD) lead that were jointly responsible for the implementation of the project and coordination of the two phases in their site. Given our objectives to identify, recruit, train and work with co-researchers, and identify local older people as participants in the study, local third sector organisations were likely to be key partners and we were keen to engage with them early. However, we also wanted to engage with older people's user groups, carers and local statutory agencies (NHS and social care) that were involved in delivering some of the services being discussed. The aim was for these stakeholders to be brought together under the auspices of a local advisory group, established early on to help support the setting up of

each case study site. In practice, arrangements and membership were fluid to enable the most appropriate people to attend.

Making progress

Experience from previous multi-site studies revealed that sites can often feel isolated, but are motivated to learn and do more when in contact with each other. This led us to design a number of All Sites Days to establish a relationship and encourage sharing – of difficulties as well of successes – between sites. The purpose was to encourage mutual learning about what works, for whom, and where; to motivate and sustain those involved; and to give opportunities for National Advisory Group involvement and programme level evaluation. All Sites Days were held approximately every six months throughout the study, and were attended by co-researchers and agencies from the case study sites, members of the National Advisory Group and (at the last event) representatives from a number of national bodies across health and social care including the Department of Health, Social Care Institute for Excellence and Care Quality Commission.

Implementing the change

Sites were encouraged to set up local advisory groups, or for an existing group or partnership structure to take on this function. Local advisory groups acted as the 'transitional mechanism' (23;77) for moving from the research phase of the project to implementation; to organise and host the local feedback event; and plan and steer the local implementation work. As we were committed to building local capacity to lead and sustain change, a key focus as the project moved into the implementation stage was on how to establish relationships and an infrastructure that was inclusive of different stakeholders. In particular we sought to ensure that, where implementation was led by statutory services, this wasn't to the exclusion of voluntary sector partners and co-researchers.

3.2.3 Research ethics

Ethical approval for the study was granted by Nottingham Research Ethics Committee 1. It is increasingly recognised that the marginalisation and vulnerability of some groups of older people is reinforced by their exclusion from fields of research (23;78). In this study, older people were invited to share and define their own experiences as participants and co-produce the study outcomes as research collaborators. These roles nonetheless raise important ethical considerations, particularly for older people with dementia who may have deteriorating mental capacity. With this in mind, the study design included the following features:

- A single academic researcher was assigned to each case study site (this role is referred to as the local research lead), thereby ensuring a continuous point of contact for co-researchers and participants for the duration of the study

- Plain language and large print information and consent sheets were designed that minimised the volume of text while ensuring all salient information was provided
- Participants were invited to have a friend or family member present during the consent process and/or interview for support
- The co-researcher training programme included a session on gaining consent and maintaining confidentiality, with opportunities to give and gain consent in a practice situation before the first interview
- For co-researchers, the study used a model of 'ongoing consent' involving regular discussion and reflection on the research process; central to this process was a debrief between the academic researcher and co-researcher after every interview
- Representatives from the voluntary sector partner acted as an alternative source of advice, guidance and support for co-researchers which was independent of the study and research lead.

In Leicester, the issue of translating information and consent materials was discussed with our co-researchers and voluntary sector LPA. They advised that written translations would be less effective than having people available who could verbally translate information and respond to questions as and when required. This role was fulfilled by the co-researchers, who were centrally involved in identifying and approaching potential participants, and who spoke eight languages between them.

In line with Mental Capacity Act 2005 Code of Practice, provision was made for the appointment of consultees in situations where potential participants lacked the capacity to consent to participation in the project. This was particularly relevant to the Solihull site. Here, two participants had lost the capacity to consent to participate by the second interview stage. Consultees, both of whom were family members, advised that it would not be in the person's best interests to continue their involvement in the study. These participants were therefore only involved in the first interview and the information they shared during this interview was included in the analysis.

3.2.4 Co-researcher recruitment and training

Information about the study and the opportunity to participate was circulated through the networks of the voluntary sector LPAs and in person by research leads at older people's groups and meetings. People interested in becoming co-researchers were asked to fill out a short application form and took part in a face-to-face or telephone interview. The interview allowed research leads to establish people's eligibility and suitability for the role, as well as giving applicants the opportunity to find out more about what being a co-researcher would entail. We initially set out to recruit co-researchers who were:

- Aged 60 and above
- Living and/or using services in the case study area
- From the same group as participants (e.g. people who have or care for somebody who has dementia in Solihull)
- With recent experience of a transition within or between health and social care services.

In all sites, co-researcher recruitment was slower than expected and therefore the first and last of these criteria were relaxed to widen the pool of potential candidates. A small number of co-researchers were under the age of 60 when recruited, although none were under the age of 55. Some co-researchers had not recently undergone a transition themselves, but nonetheless had other experiences of health and social care that gave them an insight into the research area. The aim was to recruit between six and eight co-researchers in each area to spread the load of activity across a group and avoid over-burdening individuals. Eventually, we were able to recruit seven co-researchers in Solihull, eight in Leicester, three in Gloucestershire and four in Manchester. All academic and co-researchers underwent a Criminal Records Bureau check.

A training programme was designed and delivered in a number of half day sessions over the duration of the study. As the programme was developed flexibly to meet local needs and circumstances, the number, content and format of sessions varied across the sites. For example, in Solihull the training was delivered to co-researchers who had dementia over several shorter sessions to accommodate their learning needs.

The training fulfilled three main purposes:

1. Skills development: enabling co-researchers to learn about the project and to develop or refresh the skills needed for data collection, analysis and presentation
2. Co-design: creating opportunities for research leads and co-researchers to shape the research process and outcomes together
3. Team building: bringing the team together to help build relationships and trust, and foster mutual support.

An example of co-design at the early stages of the study was in the first training session, which included an extended session devoted to co-researchers sharing and exploring their own experiences of transitions. The insights from this activity informed the development of the study's 'guided storytelling' interview approach and some of the research tools (see Section 3.2.6). For the purpose of skills development, a DVD was developed with members of a service user and carer network at the University of Birmingham with interview scenarios, to facilitate discussion about interviewing techniques and dealing with difficult situations.

3.2.5 Participant recruitment

The case study groups selected for this study include some who are amongst the least visible and most excluded from public life. The term 'seldom heard' is used to describe the under-representation of such groups in research and consultation processes, and there is increasing recognition of the factors that act as barriers to their involvement which may be attitudinal, organisational, cultural and practical (79). As the Equality and Human Rights Commission note (80):

Some marginalised groups assume that public authorities are not interested in hearing their views, are not confident about participating or are concerned they will face prejudice about aspects of their lives or experiences.

The literature on user involvement in research suggests that the way in which individuals are approached to share their views and experiences is critical. Working with trusted local networks – in particular voluntary and community groups – may be a more effective means of reaching and engaging seldom heard groups than recruiting through public agencies or popular media (79;81).

Information about the study and the opportunity to participate was circulated to older people in each case study area by the voluntary sector LPA and through their wider networks. Visits were also made by research leads to day services, groups and events to meet with and share this information with older people directly. Some co-researchers were members of local groups and/or had extensive community networks that were also used for recruitment. In Leicester, for example, over half of the research sample was recruited through co-researchers, and this approach proved particularly valuable in terms of reaching people whose first language was not English.

Participants were either service users aged 60 or above who had recently experienced the type of transition selected as the research focus in their area, or an informal carer of a person aged 60 or above who had recently undergone this transition. The sampling strategy did not prescribe that participants had to be service users *and their* carers because this would have excluded service users who did not have an informal carer, and service users who wished to participate but whose carer did not wish to (and vice versa). However, if a service user and their carer were interested in taking part, and met the criteria for inclusion, then they were accepted onto the study.

In defining the transition as having been 'recent', the primary aim was to ensure that participants could recall the salient details of their experiences and to reduce recall bias. Initially research leads sought to identify people within three months of transition but this criterion proved to be too restrictive and so was relaxed to increase the pool of potential participants and assist recruitment. The age criterion was also relaxed for the same

reason, although we still sought to recruit participants above or as close to the age of 60. Selection of participants was guided by the principles of purposive and maximum variation sampling, but also influenced by the constraints of local circumstances – especially the nature and scope of the local networks through which older people were approached to take part. While as wide a cross-section of backgrounds and demographic characteristics was sought, we do not claim that the final samples are fully inclusive of all possible views and experiences of older people in the case study areas. Further information on the participant samples is provided at the start of each findings chapter.

3.2.6 Data collection

The research methodology was based on the principles of two qualitative data collection techniques: narrative approaches and discovery interviewing. In narrative approaches, participants are invited to tell their stories in a way they prefer rather than answer questions according to a pre-determined structure. Therefore they give control to the 'storyteller' and can elicit richer and more complete accounts than other methods (82-84). For this reason, narrative approaches are well-suited to exploring the complexities and subtleties of people's experiences, and are being increasingly used in health and social care research (82;85). By encouraging reflection and enabling individuals to contextualise and connect the different aspects of their experiences, they can be particularly valuable as a way of gaining insight into complex life issues and/or events which happen over time.

Some narrative researchers propose that interview design should be completely unstructured. However, insights from the literature review and from our co-researchers suggested that it may be necessary to prompt participants about certain aspects of their experience. A review of studies of older people's experiences in acute care settings found that the narratives of experiences concentrated very little on making transitions, such as discharge planning (86). In the first training session at two of the sites focusing on going into and leaving hospital, a similar pattern emerged: when co-researchers were sharing their own experiences of transition they generally found it easier to recall and talk about the time spent in hospital, whereas processes of transition were far less memorable and tangible. A further factor militating against using a completely unstructured approach was that this might yield narratives that were very different across participants, making any kind of comparison difficult if not impossible. The issue that emerged, then, was how to design an interview approach that preserved naturalism and produced data relevant to the key research questions and which was suitable for comparison.

Discovery interviewing is a type of narrative approach that has been designed to capture patients' and carers' experiences of healthcare and is often used for quality improvement purposes (87-89). The interview is

structured by a framework – commonly referred to as ‘the spine’ – that guides the participant through key stages of their experience. The spine generally reflects the entire pathway of care: e.g. from first realising something was wrong right through to follow-up. The purpose of the spine is to trigger significant memories and thoughts, rather than to set out an agenda for the participant to follow.

Drawing on the discovery interview method, two spines were developed for the project, one for each of the types of transition that had been selected. The spines were based on the conceptual framework (described in Chapter 2 and represented in the diagram on page 27), so that they captured the full transitional journal from antecedents, through triggers and processes, to consequences (see Figure 6). Given the longitudinal nature of the study, the spine included both current and anticipated consequences of transition. For example, for the transition into and out of hospital, these consequences were defined as ‘life back at home’ (current) and ‘hopes and fears for the future’ (anticipated). Each stage was printed onto a small handheld card to be used if necessary during the interview. In addition, two further tools were developed to support the first stage of interviews:

- A visual representation of the transition (see Appendix 1 and 2)
- A series of prompt questions that could be used to elicit further information.

Interviews started with a short preamble, explaining the purpose and format of the interview, after which the following opening question was asked: ‘We would like you to tell us about your recent experiences of [type of transition]. If it helps, please use this picture to remember what happened and share your story with us. Start wherever you like and please take as much time as you need.’ Interviewers could use the three tools (spine cards, visual representation and prompt questions) as and when necessary to suit the circumstances and participant, rather than following a one-size fits all approach. The spine enabled researchers and co-researchers to identify any gaps in the story as initially told, so that as full an account as possible was elicited. Given the emphasis within the study on influencing service change, interviews concluded with two specific questions asking participants for suggestions about how services for older people could be improved.

Figure 6. The interview spines

<p>Going into and leaving hospital</p> <ul style="list-style-type: none">• The events leading up to going into hospital• Going into hospital• Being in hospital• Preparing to go home• Going home• Life back at home• Hopes and fears for the future <p>Receiving services for dementia for the first time</p> <ul style="list-style-type: none">• When you first noticed something was not right• Doing something about it• First contact with services• Receiving help/services• The help/services you are getting now• Living with dementia• Hopes and fears for the future
--

Participants were invited to take part in a second interview – approximately six months after their first – which explored how their needs and experiences had changed over time. Before each follow up interview, the research lead and co-researcher met to review the transcript from the first interview and agree areas to follow up. Again a narrative approach was taken: after the interviewer had given a short summary of the main points from the previous interview, participants were asked a general question about what had happened to them in the intervening period. Areas identified for follow up from the previous interview were addressed afterwards.

Interviews were arranged by research leads, who explained the co-research model to participants and gave them the option of being interviewed with or without a co-researcher present. In all but two cases, participants agreed to speak to the research lead and a co-researcher. Participants were also given the option to have a friend or family member present during the interview

and this invitation was often taken up. The majority of interviews were carried out in participants' own homes, with a small number taking place in local community venues. At the start of the interview, the purpose of the research was explained and the format of the interview outlined. Where the participant was a carer it was emphasised that the purpose of the interview was to find out about *their own* experiences of the transition, not for the carer to re-tell the experiences of the person that they cared for.

In advance, research leads and co-researchers discussed what roles each would take during the interview and who would be responsible for practicalities such as turning on the digital recorder. It was made clear to co-researchers that there was no expectation about the role that they would play, and that they could develop or change their role over time. Some co-researchers wanted and felt confident to lead interviews from the outset; others opted for a different role (e.g. asking follow up questions). In Leicester, ten participants asked to be interviewed in their first language – either Gujarati or Punjabi – and these interviews were entirely led by a co-researcher who spoke the relevant language.

3.2.7 Data analysis

All interviews were digitally recorded with the permission of the participant and verbatim transcribed. Where necessary they were also translated into English. Transcripts were anonymised and participants' identifiable information was kept separately and securely. The data analysis was guided by the principles of framework approach (90), an analytical process which combines inductive and deductive elements. This is carried out through the identification of *a priori* themes and categories derived from the research questions and/or existing literature, to which novel themes and categories are later added as they emerge from familiarisation with the data. This approach is particularly well suited to the problem-oriented nature of applied research, whilst also allowing for an analytical process which remains grounded in and driven by participants' accounts (91).

Data analysis was an iterative and collaborative process, which necessitated regular meetings between members of the research team. Initially, research leads familiarised themselves with the transcripts from the interviews that they had carried out, and recorded all themes and issues arising from the raw data. Excerpts from transcripts and the researchers' initial reflections on the findings were then shared and discussed. It was evident that the data contained common patterns and themes, as well as issues that were unique to a particular site or where meanings assigned to those issues differed within and across the sites. This necessitated an analytical framework that preserved the distinctiveness and nuances in the individual datasets, whilst also providing a robust basis for comparing experiences across the different types of transition, older people's groups and geographical areas involved.

To this end, a three level hierarchical coding framework was developed incorporating universal and site-specific elements. Following the framework approach, this process of development involved deductive and inductive reasoning. The top level of the framework was comprised of the seven stages of the transitional pathway (the spine), derived from the conceptual framework and which had been used to guide the interview process. This conceptual model was informed not only by the literature review, but also by the co-researchers own experiences of transition as shared at early training events. A series of six overarching descriptive themes emerged from ongoing comparison of the four datasets, which formed the second level of the framework. These were: attitudes and feelings; coping and management strategies; emerging and unmet needs; personal and relationship transitions; services; and social support. Written definitions for these overarching themes were produced to ensure that they were being consistently interpreted and applied. Finally, the third level of the framework was populated by each research lead with more detailed sub-themes (descriptive and analytical) that emerged from the data gathered in their own site.

Each researcher coded the transcripts from their sites, using NVIVO data analysis software, and at regular meetings shared new themes and insights and considered any emerging data issues. The datasets were initially analysed separately and the results of this level of analysis are reported in Chapters 4-7. Comparison of experiences across the sites was an ongoing feature of the analysis, as well as being specifically discussed with representatives from the local sites at the third All Sites Day, and by the research team at a half day comparative analysis workshop. The main focus of the comparative analysis was to explore what the data revealed about the relationship between transitions as they are understood and experienced by older people, and as they are structured and managed by health and social care services. We sought in particular to identify where there were common themes across one or more of the sites that may be suggestive of universal aspects of care transitions and how these are experienced by older people.

In each area steps were taken to include the perspectives of co-researchers in making sense of the data and in identifying the main issues to share with local stakeholders in feedback events. The precise nature of co-researcher involvement in data analysis and the approach by which this was achieved was agreed at a local level, rather than being mandated by the study team, in order to take account of co-researchers' expectations and preferences. Therefore the methods of co-analysis differed between sites. As an illustration, in one site a data analysis workshop was held during which co-researchers, the research lead and a representative from the voluntary sector partner organisation read through excerpts of transcripts together and discussed the key themes they had identified. The debriefs carried out at the end of each interview also provided a useful opportunity for research

leads and co-researchers to reflect on what they had heard and consider the main issues and insights from the experience shared.

3.3 Evaluation of the participatory approach

Despite the growing body of literature on user involvement in research, there is little evidence of formal evaluations of participatory approaches (16) and limited evidence on the impact of lay involvement on research processes or outcomes (58). We must not therefore simply subscribe to the notion that this is 'a good thing' (15) but rather, as Dewar concludes, 'move beyond anecdotal accounts and...be critical of why it is important to involve users' (17). In undertaking this research study the research team therefore built in an evaluation of the participatory approach with a particular focus on the involvement of older people as co-researchers. In so doing we were concerned to focus not just on the effects of their involvement on the way in which the research was conducted, but also on the changes that the research might bring about.

The overall purpose of the evaluation was to explore the impact of the participatory approach on the research process and outcomes. Two key caveats were identified from the beginning. First, in qualitative research of this nature, involving complex social interactions between individuals, organisations and systems, framed within a changing policy and political context, it is very difficult to attribute change or impact to one particular part of the process (58). Second, impact or change is not necessarily immediate or short-term; sometimes the effects of an approach can take a long time to filter through (58). Furthermore, we chose not to have a control group in the study (which would not have included co-researchers) so we can never be sure what would have happened had we adopted a more conventional methodological approach.

In undertaking the evaluation the research team sought the views of key stakeholders in the four sites: co-researchers, academic researchers, and statutory and voluntary sector LPAs. We were not able to ask research participants about their perceptions of the participatory approach, namely the presence at the interview of an older co-researcher, as limited time and resources prevented this. Instead, we relied on the interviewers present to comment on how they thought their involvement affected interviewees.

In designing the evaluation, the research team adapted a framework developed by INVOLVE to review evidence of the impact of public involvement in research (58). We therefore sought to answer the following research questions:

- When and how the participatory approach affected different stages of the research
- Who was involved and the impact on these different stakeholders

- What difference the approach made in terms of implementation and change
- What helped and hindered in terms of achieving impact
- What we have learnt from this approach.

The evaluation was deemed independent in that it was undertaken by three members of the research team who had advisory roles and were not involved in data collection and analysis. Once the project had commenced, they undertook semi-structured telephone interviews with the lead from all four voluntary sector LPAs, three of the statutory LPAs and interviewed the four academic research leads (see Appendix 3 for the interview topic guides). Two focus group were held to elicit the views and experiences of the co-researchers. The first was held on the first All Sites Day and involved six co-researchers from three of the sites. The second focus group involved four of the co-researchers from the fourth site. At this stage each of the stakeholders were asked the same three questions:

- What motivated you to become involved in this project?
- What has been your experience so far?
- Do you have any thoughts about the future outcomes of the project?

A follow-up was carried out once the local fieldwork was complete and the project was nearing its end. This involved interviewing the leads from two of the statutory LPAs and six people from the four voluntary sector LPAs, and undertaking three focus groups and five individual interviews involving 15 of the co-researchers. They also interviewed the four academic research leads and the two OD leads. Again, the interviews and focus groups were structured around the same five questions:

- What has being in the project meant for you?
- What has helped and hindered the participatory approach?
- What has been the impact of having co-researchers in the study?
- How do you think the findings can make a difference?
- If we were doing this study again, how could we improve it?

The interviews were carried out by a single researcher and the focus groups by two researchers, one of whom led the group and the other took notes. Each encounter was digitally recorded with the permission of the participants to use their exact words anonymously in the final report. The researchers also took detailed notes which were subsequently shared. They familiarised themselves with all the material and one researcher wrote a summary of each group of the key stakeholders' perspectives. Common themes emerged based around the key research questions above asked of all the respondents in the two stages of the evaluation. The themes were analysed by reference to both their impact on different stages of the

research design and by impact on the different stakeholders. The findings are reported in Chapter 9.

3.4 Summary

The challenge of implementing research into policy and practice has long been documented and, on this basis, the potential of action-oriented approaches has been emphasised. A key feature of such approaches is co-production, where local people actively shape and create the research process and its outcomes. This contrasts with more traditional models of research where the role of 'participants' is usually limited to being the supplier and/or end user of information, gathered through a process which is often outside their control. Drawing on a wide body of methodological literature, this study was designed to achieve co-production in order to enhance the ownership, usability and perceived validity of the findings for the case study sites involved. The two main features of the study design – the local partnership infrastructure and co-research model – have been described in this chapter, and the factors that have influenced the design process also discussed. As we note, participatory research (in all its forms) requires careful consideration about how meaningful collaboration and involvement can be secured and tokenism avoided. Above all, this means addressing the methodological and practical challenges that arise when opening up research processes to different interests, perspectives, knowledge and expectations. The evaluation of the study's innovative participatory approach was intended to assess the extent to which co-production had been genuinely achieved, and the consequent impact on the research and its findings.

4 Older people who have dementia (Solihull)

4.1 *Background and context*

4.1.1 The local area

Although Solihull as a whole is an affluent borough, it is also one of the most polarised. Whilst wards in the south of the borough rank amongst the most affluent nationally, three wards in the north fall within the 10% of most deprived areas. On average people living in the North of the borough die ten years before those in the South. North Solihull, combined with East Birmingham, has been designated as one of six Regeneration Zones in the West Midlands.

Based on 2001 census figures, Solihull has a population of 199,521 of whom 33,583 (16.83%) are aged over 65. Demographic projections indicate an increase of 46.8% in the population of people over the age of 65 by 2031 and an expected increase of 138% in those aged over 80. As the prevalence of dementia increases with age, this steep increase in the number of 'older old' people is significant. It is projected that by 2031 there will be a 47% increase in the number of people with dementia in Solihull. The ethnic minority population comprises 5.41% of the Solihull population, compared with 8.7% for England and Wales.

4.1.2 The study in Solihull

Birmingham and Solihull Alzheimer's Society was identified as the voluntary sector local partner agency (LPA) for this site. Although its central office is in South Birmingham, it also has a local centre on the outskirts of Solihull. It was this centre that provided the main point of contact and support for the study. Solihull Care Trust was the statutory LPA. The Care Trust was formed in 2006, integrating NHS and adult social care services. In response to NHS reforms to separate commissioning from the provision of services, Solihull Care Trust was redesignated Solihull Primary Care Trust on 15 April 2011, with responsibility for adult social care reverting to the Metropolitan Borough Council (SMBC). The main contact within the Care Trust was the Commissioning Lead for Adult Social Care Services, whose employment reverted to SMBC in the latter stages of the study.

Following discussion with the LPAs, it was decided that the main transition focus would be on entry into dementia services. An enhanced memory assessment pathway had recently been implemented, along with the

introduction of two new dementia advisor posts, one in the North and one in the South of the borough.

Seven co-researchers were recruited through the voluntary sector LPA, either through direct contact with the researcher at a memory café, information distributed by outreach workers or a notice published in the organisation's newsletter. Four co-researchers were older people who were carers of people with dementia and three were older people with dementia. All were of white UK ethnic origin; other characteristics are shown in Table 3.

Table 3. The Solihull co-researchers

Name	Gender	Age	Living situation	Experience of dementia
Joe	M	80	Lives alone following the death of his wife	Former carer of his wife
Terry	F	65	Lives with husband	Cares for her mother who lives in flat opposite
Val	F	69	Lives alone following admission of her husband to a care home	Cares for her husband, whom she still visits frequently
Elizabeth	F	73	Lives with husband	Cares for her husband
Barrie	M	75	Lives with wife (Elizabeth, above)	Has dementia
Mike	M	66	Lives with wife	Has dementia
Jane	F	58	Lives with husband	Has dementia

4.1.3 Participant characteristics

Nine participants were recruited by the voluntary sector LPA through the same means as the co-researchers. However, as recruitment proved problematic, co-researchers also distributed information about the study amongst their informal contacts and succeeded in recruiting an additional two participants. This brought the total number of participants in the Solihull site to eleven. Six participants were carers of people with dementia and five were people with dementia. As with the co-researchers, all were of white UK ethnic origin. Participant characteristics are summarised in Table 4.

Table 4. Solihull participant characteristics

Name*	Gender	Age	Living situation	Experience of dementia
Gordon	M	70	Lives with wife	Has dementia
Harry	M	71	Lives with wife (Sylvia)	Has dementia
Reg	M	69	Lives with wife (Betty)	Has dementia
Edna	F	77	Lives alone	Has dementia
Penny	F	57	Lives with husband (Philip)	Has dementia
Sylvia	F	69	Lives with husband (Harry)	Cares for husband who has dementia
Ken	M	72	Lives alone	Cared for wife who has dementia and is now in a care home. Visits frequently.
Betty	F	69	Lives with husband (Reg)	Cares for husband who has dementia
Philip	M	63	Lives with wife (Betty)	Cares for wife who has dementia.
Linda	F	55	Lives with husband, teenage daughter and mother	Cares for mother who has dementia
Anne	F	65	Lives with husband	Carers for husband who has dementia

* All participant names are pseudonyms

By the time of the second interviews, two participants with dementia no longer had the mental capacity to make a decision about participation in an interview and their carers felt that a further interview would not be in their best interests. Therefore, only nine participants were interviewed for a second time, bringing the total number of interviews carried out to 20. All participants were interviewed on their own, with the exception of Gordon, who chose to have his wife (Eileen) present.

The original intention was to focus on experiences of entry into dementia services. It was hoped that the recently created dementia advisor post would be a useful source for recruitment of people recently diagnosed with

dementia and starting to receive services. However, the Solihull Dementia Advisor received a low level of referrals during the period of recruitment and very few existing users of Solihull Alzheimer's Society who met the criterion of recently entering dementia services were identified. The study focus was therefore widened to include people with dementia and their carers who had recently experienced a transition into, between or within dementia services.

4.2 The research findings

4.2.1 Awareness, understanding and acceptance of dementia

Participants' experiences of seeking and receiving help for dementia were influenced by their own and others' levels of awareness of the condition and how they perceived it. For example, early signs of memory loss were easily dismissed as 'old age'. The stigma and fear of dementia could delay acknowledgement of the difficulties by the person with dementia and their family. Equally, it seemed that the negative social construction of dementia led to reluctance by doctors to deliver the diagnosis, with a tendency to rely on alternative terminology. As the difficulties with recruitment to the project demonstrated, such factors could then act as barriers to individuals and families accessing support from specialist dementia services, such as the Dementia Advisor.

Acknowledging the problem

Some participants with dementia did not realise they had a problem until this was raised by their carer or others, or until something in particular happened that highlighted the change in their functioning:

Well it didn't actually occur to me that I had a problem. I don't know whether the driving, I lost my way where I was going, so I was coming off the motorway and going home and I got lost, I think that probably was the first time. (Gordon)

Even when the person with dementia or carer realised that there might be something wrong, there was often a period of 'putting up a barrier' so that this was not openly acknowledged:

I suppose, deep down inside [I knew], but it's something you don't want to hear, you know, you sort of, put a barrier up against it and it's still a shock when somebody tells you. (Philip)

Other explanations were frequently found to account for changes in behaviour:

He was saying, 'Oh, my memory!' and I was saying, 'Oh, your memory!' you know, little things. And we just thought it was part and parcel of, as everybody does, you go into a room, 'What did I come in here for', sort of thing...[It was] a slow decline...it's such a gradual thing...you just thought it was just old age. (Sylvia)

Receiving a diagnosis

Most participants did not feel they had been given a clear diagnosis of dementia. Lack of clarity on the part of doctors about the diagnosis could reinforce people's avoidance of the situation, rather than helping them to engage with it:

When we went to the doctor's...he said it was short term memory loss, and my daughter said, 'He didn't say Alzheimer's, did he then?', and I says, 'No he didn't'. So you're all like clutching at straws, really, you are, just hoping that a miracle will happen. (Sylvia)

I think Mr T [a consultant], at the beginning said, the words he used was short term memory loss. And he said, what happens is the short term memory brain cells die off and they don't know why that's happening. So, actually, Alzheimer's or dementia was not mentioned, as such...I usually sort of use the words 'short term memory'. (Eileen)

The way in which the diagnosis was communicated could have a lasting impact on how people viewed the dementia, whether it was seen as a threatening and uncontrollable force or a more benign and manageable condition. One carer described in detail a seven year period of being passed between clinicians, none of whom gave any clear communication about what was wrong with his wife. Eventually they were referred to a general physician:

We thought somebody was paying attention and he'd looked into things very clearly...And we placed a lot of store in going back to see him...and we subsequently went back and, as so often happens, we saw another doctor and he started talking to us as though there were no specific changes...And I pulled him up and started questioning him. I said...'We're concerned because things are getting worse with my wife and, you know, we wonder where all this is leading?' And he kind of jumped at me and said 'Do you always ask questions like this?' and I said 'Yes, when it gets to this sort of stage, we do'. He said 'Well it's patently obvious what's wrong with your wife, everybody knows what's wrong with your wife, don't you?' And he got quite nasty and I said 'No, we don't', he said 'Well she has FTD'. I said 'What the hell is FTD when it's about?' He said 'You don't know what FTD is?' I said 'No'. He said 'Nobody's ever said frontal temporal dementia to you?', and I said 'No'. He said 'Well that's what your wife's got'. And he really lashed into us and he reduced my wife to absolute tears and we both came out of there totally distraught and I think that was, kind of, the beginning of the end, a real turning point in this whole thing, because it had taken seven years of back and forth and several sort of tests before somebody had socked us between the eyes and out of the blue with this diagnosis. (Ken)

In contrast, a diagnosis of dementia, sensitively communicated, could bring relief after months or years of uncertainty:

I think, even to [husband], it was almost a relief when you did get a diagnosis of dementia...the word dementia gave you a sense of, I've now got a label to what's the matter with me...something which is solid, as it were. (Anne)

A dementia diagnosis could be useful in explaining, both for self and others, the difficulties experienced:

I'm feeling what comes on and thinking oh that's got to be the dementia...If I do something dippy or if I'm thinking and I think you're going again, you know, and I suddenly realise...it could be the brain, you know, the dementia...Once this came it was things keep, every so often, something pops up and I think it's your dementia, you know, you just have to accept it. (Edna)

4.2.2 Seeing the Whole Picture

Another key factor influencing participants' experiences of moving into and between dementia services was the extent to which service providers engaged with and were responsive to the whole picture of the circumstances of the person with dementia and relevant carers.

Family context

How participants experienced dementia was shaped by the context of their relationships with partners, family and friends. One carer had brought her mother, who had dementia, to live with her and her family. She explained:

I want to do it, yes I do. I don't know how long I've got my Mum for, do I? I mean the age she is...she's getting close to 90 now. I want to do it as long as I can...I know a lot of people don't want elderly people living in their homes and I think it depends on the relationship you've had with that parent, if you can do it or not. If I hadn't had the relationship that I've had with my mother, there's no way I would be doing what I'm doing. Only because she's been wonderful, a wonderful mother to all three of us. (Linda)

Carers wanted service providers to recognise their central role in supporting people with dementia and also to be sensitive to the dynamics of these relationships. One carer mentioned the difficulty of being expected to talk in front of their partner at medical appointments:

And he [the doctor] asked me questions and, I mean, I got upset because you feel as if you're betraying them somehow...You don't want to tell the truth, especially in front of them...That's how I felt...and I thought well, you've got to say what's going wrong, sort of thing, otherwise there's no point in being here. (Sylvia)

Participants valued professionals and services that recognised that the wellbeing of the carer affected that of the person with dementia, and vice versa. One carer with Parkinson's said:

The only sympathy that I've engendered or witnessed in that regard has been from the care home again. They've asked me, 'Are you alright, what's going on, you don't look well today, are you having a problem?' and...I suppose, from their perspective, they're worried about [my wife] and they realise that what's happening to me is impacting on her, just as what's happening to her is impacting on me. (Ken)

Other health problems

Four of the five participants with dementia were living with other health difficulties alongside the dementia. These included diabetes, stroke, arthritis and epilepsy. Although partners were seen as 'carers' by dementia services, three of the six carers were also 'patients' in their own right by virtue of medical conditions including heart conditions, Parkinson's Disease and depression. The interface between these different health problems was sometimes not identified or addressed by service providers, who operated within the narrow remit of their own speciality. One carer had very serious heart problems which he felt were aggravated by the stress of caring for his wife. She, in turn, was aware of the risk to his health caused by the delay in his treatment:

It's not getting any better and they're not doing anything for him which is really annoying me. I'm getting cross with them now. They're supposed to have had this cardio-vascular thing that he's having and they're not doing anything about it. And they've told him that he's got to have it done fairly quickly. And they're just not doing anything. That is really, really annoying me. (Penny)

Her husband felt that her increased agitation, in turn, generated more behaviours that he found difficult to manage, thereby creating a vicious cycle of stress and anxiety.

Another carer, who had previously suffered a heart attack, could no longer leave her husband alone. Consequently she had to give up the physical exercise that was important in protecting her own health:

I went swimming every Wednesday, it was called the Nifty Fifties club down at the swim baths and I loved it. It was good for me because I had a heart attack two years ago. And I started then, I loved it, but I had to stop going because I can't leave my husband on his own. (Betty)

4.2.3 Doing battle with services

When trying to access dementia services or change or increase services, the predominant metaphor used by participants was of 'fighting' or 'doing

battle'. However, although some participants took an active stance, seeking out help and challenging services, others were more passive, feeling that it was not in their nature to make demands or that they did not have the physical or emotional resources to do this.

Getting helpful information

When seeking help, participants often felt that they were engaged in a battle with doctors to force them to listen, understand and take action. This was exacerbated by a lack of continuity in the clinicians seen at appointments and the poor coordination between them:

Gradually things got worse and it became more and more difficult to get people to pay attention, it seemed that...the doctors just didn't seem to know what to do and it was, you're kind of left to your own poodling devices, just staggering along...it seems, looking back, that there was never any continuity between the phases. People seemed to be doing their own little thing, their own specialised medical knowledge and there wasn't a continuity of progression of looking for something that was going to be the root cause of the problem...I was, as time progressed, singularly unimpressed by any form of direction. Pursuing their investigations, it just seemed pointless and endless, the verbal questioning and the standard tests that took place and it seemed to be going nowhere...It all seemed disjointed and going through motions and they were just there going through motions. (Ken)

Another carer also felt that consultants were 'going through the motions' of offering regular appointments, but that this did not achieve anything tangible:

[Husband's name] was seeing consultants, but we weren't getting answers to everyday living, so you come back and we'd just think, well, where do we go from here? The only decisive thing was telling [husband] he mustn't drive, but there was nothing else. Only [name of doctor] suggested the Alzheimer's Society, but we were already a couple of years into dementia before we saw [that doctor]. (Anne)

Finding out about services often seemed to occur by accident, as a result of chance encounters. The carer whose mother had moved to live with her had been looking after her for a considerable time before they received any services. She explained:

I think how it worked – we were going on holiday and my husband's partner's wife said 'Oh have you got a social worker?' and he said 'No', and she said 'Well if you get a social worker you'll be able to use respite'. Didn't know a thing about it. So if it wasn't for her I would never have known anything about respite. Nobody actually pointed out these things to us. (Linda)

There was a sense that services were, at best, reactive, but did not initiate the giving of advice or information. This had to be actively solicited, and at

the beginning of their dementia journey, participants did not necessarily know the relevant questions to ask.

What I've found with social services, they would answer a question, but they don't talk around it or tell you anything that you haven't asked. So if you don't know the questions to ask, you don't really come away thinking, you know, and you think, tell me what my options are. (Anne).

Getting the right help at the right time

Once participants had gained entry to services, they often faced difficulty in obtaining additional or different forms of help when they needed it. This was sometimes about delays and waiting lists:

The social services, this happens very, very slowly. It took about four months for someone to come and see me and then it took a further three months [from there]...it does take a long time and I think a lot of carers would say the sufferer has changed while you are actually waiting. (Anne)

One carer described having to make himself persevere with demanding the help his wife needed, even though this made him unpopular with services:

I decided that I've got to do something, if it's only to satisfy myself and my conscience that I'm doing the best for [my wife] because this is what it seems has happened all the way along. You know...chasing the system, finding out how it works, having to push and shove and cajole yourself. Nobody comes to you and says we should be doing this or we should be doing that. (Ken)

Another carer mentioned being continually referred on from one agency to the next when trying to obtain support in caring for his wife. He described how each organisation he approached 'batted away' his request for help:

That's all they do. They just bat for England. (Philip)

He also made the point that information giving seemed to rely exclusively on sending out leaflets:

People phone you up, and 'Oh, let me send you another package'. And I say 'Look, there's only so many hours in a day that you can read all these bloody leaflets, all this paperwork on dementia and Alzheimer's'. You know, you get heart and soul sick of it. That's why I said to the girl the other day, 'Look, just don't send me any more packages'. (Philip)

These experiences contrasted with the service one participant had received in the area in which she had lived previously:

We had a lady and she was marvellous, she was the most helpful lady that there was...she was an outreach sister, so she's out in the community. She was with us virtually all the time. She didn't just come

and say 'Hello, how are you?' for a few minutes. She'd stay with us and if there was anything that was worrying us, she'd be there'.
(Penny)

4.2.4 Living with dementia

Although the research focus was on transition into or between dementia services, the prime focus of participants' accounts was on living as well as they could, despite the difficulties presented by dementia. All participants were engaged in a process of trying to 'carry on' or 'make the best of it'. However, this was complicated by the continual changes and transitions that having a dementia or caring for someone with a dementia entailed. Services could either help or hinder people's ability to live well with dementia.

Getting on with it

Participants with dementia were resolved to continue with their lives despite their dementia, 'making the best' of what life still had to offer:

And [I] go along with it. It's you know, it's something that it comes and it goes and you can still carry on living, you know, which is what we have to be thankful for!...At the end of the day there's absolutely nothing you can do about it but carry on enjoying life. (Edna)

I don't really think about it to be honest. I don't think about what I've got any more. I just think get on with it and, you know, that's all you can do. (Penny)

However, during the course of the research, some participants' lives became more restricted as a result of loss of confidence and declining cognitive abilities. One carer said of her husband:

I've noticed as well that...he's quite content to sit and watch the telly and to get him moving is getting harder and harder...Whereas at one time he could go out driving on his own, or go and meet a friend, he can't do it now...Trouble is he can't do anything without me because he just gets lost. (Sylvia)

In trying to 'get on with it', participants adapted and usually restricted their usual way of life to accommodate their changed abilities. One person with dementia talked of feeling 'imprisoned' by dementia:

The thing that I still find frustrating is this belief, really, that I'm in a prison cell but they're letting me out under a license, which is how I see it. (Gordon)

The role of family and friends

The interviews highlighted the vital role played by family and friends in helping people adjust to living with dementia:

I'm lucky because I've got lovely friends and they all sort of, they're all there for me sort of enclosing me in this...my friends they're brilliant...they'll come over to see me and they'll grab hold of me and they'll say come on, we're going out and I think that's the best thing you can do. (Penny)

Participants with dementia were very aware of the impact that living with dementia had on their partners' lives and very grateful for the role they played in helping them to manage:

Dementia is having an effect on the people that you're living with. And that's very difficult at times...Perhaps I don't, sort of, say often enough how much I appreciate what my wife is doing...I mean, bless her cotton socks, I mean, she deserves an Oscar...she is the one who needs congratulations and whatever, she's been amazing. (Gordon)

I don't actually go out on my own, not now...I've got a good wife, you know, she does look after me...We get on great. But I don't want to put it on her, you know, I don't want to put any pressure on her. But that's what we're together for isn't it?...You need help, you need somebody to be with you all the time don't you like? Work with you. You don't have to sit and wait for them to come back you know. Need somebody there with you...Just a matter of being there. (Reg)

They were concerned about burdening their partners and, when asked what message they would like to give to services, the most common response was 'help the carers':

The only thing I can think of really is not so much for me it's for my wife. You should have people come and see the wife, have a nice discussion with her. I think that's what it should be really, because it must be frustrating for her at times. (Harry)

The role of support services

The interviews highlighted the crucial role of support services in helping people make the transition to a life with dementia:

I go to a dementia café as well, one Wednesday in the month and that's lovely...Yes, I love it, absolutely love it, we have our lunch and we all have, we're all sitting there having a talk, it's lovely. (Penny)

Often it was the personal qualities of individual workers that were the focus of comments:

I've had all sorts of people and every one of them have been lovely, really lovely, so helpful, I couldn't fault them. (Betty)

Another carer commented on the practitioners who did not just 'talk the talk', but who had 'something special inside', showing a passion and relentlessness in their desire to help.

The continuity of support provided by one key person with whom carers could form a relationship was particularly valued. Two carers identified the social worker as playing a key role in this respect. They might not need to contact the social worker very often, but knowing that there was a trusted person they could call on if necessary was a source of comfort and reassurance:

She's marvellous I think she's my angel, honestly...I probably only see her twice a year, but I know she's at the end of the phone and I know she'd do anything to sort it out (Linda)

However, not all participants had this experience. Another carer talked of the difficulty of contacting her social worker:

I never see her. I ring her up, I never get to talk to her. I talk to, I don't know if she's a secretary or not, but I'm putting him into respite for two days...I'm waiting, that's why I keep ringing [the social worker] because she's never got in touch with me. (Betty)

While participants who had been 'in the system' for some time had access to social workers, this seemed not to be the case for those more recently referred. One carer talked about his relief at finally getting a social worker to visit him and his wife, but then his disappointment at the service offered:

The [social worker] sat there, and then he got up, I said 'Well, it's been really nice meeting you. So you're now the allocated social worker for [my wife]'. And he said 'Yes, that's right'. And I said, 'Oh that's great, so when will we see you next', and he said, 'Oh you probably won't'. And I went 'Pardon?' He said 'Oh, you probably won't, you know, with all the cuts'. And I said, 'Well, I thought as my wife's social worker you'd now build up a rapport with her and come and see her, she'll be on your case file and all that'. And he said, 'Oh no with all the cutbacks, I'll probably never see you again', and true to his word, I haven't seen him since. He's phoned me, I think, once or twice but I haven't seen him. (Philip)

For carers, part of the value of establishing a relationship with practitioners was having their own needs recognised and feeling that they were cared about as people. One carer highlighted the need to feel a personal connection with service providers and to be seen as a 'whole person'. She saw this as more likely to be communicated by voluntary organisations:

Solihull Carers are very comforting people to know, they will find answers for you. We were dragged all the way down to [hospital in] Cambridge and...we did get the impression that people were only interested in, sort of, your brain but not you, as a person but...the kind of personal help seemed to come from Solihull Carers. (Anne)

In terms of specific services that were valued, three carers mentioned their appreciation of a carers' training course that ran over several weeks and

provided a range of information that helped them to feel more equipped for their role and for what might lie ahead in the future.

Carers believed that it was important to help the person with dementia to keep active and socially engaged and they made considerable efforts to do this, thinking of activities to structure the day and organising their own lives around providing these. Day centres or memory clubs that enabled people with dementia to interact with other people and participate in enjoyable activities were highly valued. However, opportunities for individuals with dementia to engage in activities that were meaningful to them were scarce. In this sense, being given a budget to purchase their own services was experienced as of limited value:

I find that my husband will sit and just look at the walls and if I don't talk to him, he doesn't initiate conversation. We've now got him in a day centre locally [but] it's not ideal. I would like him to have more male company and a group of people who would perhaps go out with him because he does like outdoor activities like walking, but I have found that they just do not exist...We do get a disability living allowance and quite rightly, they'd say, well then you pay for his day care out of that. But there isn't a vast choice of things to pay for out of it, you see. It's not as if I'm thinking, 'Oh well there's some wonderful things, you know, I could, now let me see what will I do this month? I know, I'll put him there'. Well there's no real choice. (Anne)

4.2.5 Negotiating change

People with dementia and carers experienced lives of continuous change, both in the present and in how they anticipated the future.

The impact of dementia

Dementia itself was perceived as the cause of significant changes to the individual, with this in turn triggering change for those in the informal network. One carer described how her life changed when her mother came to live with her:

The change in my mother, it was like I was looking after somebody completely different. You know we planned to move. I planned to go and work in my husband's company, I'd been to college and I'd got all my skills up on computers, so I was going to completely do that and it completely changed overnight. (Linda)

For others, the change was more gradual, as life slowly became more restricted:

So our world is shrinking in a way, unless I take him somewhere and he's going to be occupied, then I'm with him. (Anne)

I watched a lady on the telly here and they asked her, 'What's it like being a carer?' and she said 'Well obviously, you give everything you

can for your partner, but the most important thing is, as long as you realise that your life, as you knew it, has now finished, you'll be fine'. And I sat there and I thought, bloody hell, that woman is so right...I mean, my life and the kids' lives have just been turned upside down, so dramatically, and there must be so many other people in the same situation. (Philip)

Managing continuous change

It was readily apparent from the second visits to participants that their situations were characterised by continuous change, rather than specific transitions. Carers had to find ways to manage new problems as the dementia progressed. This was evident in the changes that occurred between the two interviews:

Yeah, well things I think are deteriorating a little bit, you know, he just doesn't remember now most days, it's a fluke if he remembers what day it is. I find that he's starting to get a little bit more nasty now and I think that's frustration isn't it? I was saying something to him last night and I said 'You haven't grasped that have you?' 'No' he said, 'tell me again', so I started to tell him again. 'Oh, it's you, you're thick'. And it's so hurtful, you know. But he forgets it, you see, but it's that sort of thing, it's just very fiery, quite aggressive. (Sylvia)

As one carer described it, they might find a way to deal with one problem, only for that difficulty to change or new ones to emerge. For carers, there was a sense of always having to be on their toes to anticipate the next challenge:

[He's deteriorated] a lot, since you come the last time...I mean, I can't move, he wants to know where I am all the time, what I'm doing and he's just, all the time. But oh he's definitely getting worse, keeps wetting himself now...if we're out or anywhere, he can't hold it at all and every time we come back he wets himself, he's soaking wet...And you know, the other? He hates it, he can't help it. (Betty)

Even if an assessment had been carried out within the last couple of months, carers could feel that this was now out of touch with the current situation. However, as noted previously, some of them experienced difficulty in getting services to respond to requests for a review.

Even if services were increased, this could prove difficult to manage if these were not well coordinated or explained:

I'm getting so mixed up. I've got so many [people coming]...I says to that [support worker], 'I don't know who's coming and who's who'. There's that many people coming now. I don't know who I'm talking to half the time. (Betty)

Two carers, in particular, were feeling unable to cope. One began taking medication for depression in between the two interviews and another talked openly about his feelings of desperation:

There are times when Penny goes to bed at night...and I sit here and I cry my eyes out and I just think, I can't cope with this anymore...I don't mean to be over dramatic about it, but I'm just digging myself an early grave and, to be quite honest with you, I don't care. There are times when I've said to Penny, 'I wish we both weren't here'...and, you know, I've said to Penny, I just think, 'Oh let's just make a nice hot chocolate together with you know, a ruck of tablets in and just go to bed and frig 'em all'. Sorry, I just get like that. (Philip)

The future

Participants had to contend not only with change in the present, but also with the knowledge that their situation would deteriorate in the future. As one carer said:

I don't know how things are going to end up. I try to take each day as it comes, I do, because that's all you can do, isn't it, really...But I just think how things are going to end up. (Betty)

Lack of knowledge about the support that will be available to help with future need compounds the difficulty of coping in the present. One carer talked about her worries about how she would manage financially if her husband needed to go into a care home. She also felt anxious about what would happen to him if she were no longer there to care for him:

It's just the not knowing, which nobody knows how long they're going to live or whether something's going to happen to me first. I mean that's a worry...Because I think, oh please God, let me be all right. (Sylvia)

Another source of anxiety was about valued services being cut. One carer said:

I'm hearing lots of bits from the carers [at the day centre] where they're worried about their jobs and worried about the centre going, because so many of these centres are going...Many of them that bring my Mum home are going, 'Oh, we're really worried about our jobs, we wonder if we're going to lose the centre?' I mean my life would change overnight if that happened...I would be worried about the centre closing, because it affects everybody then, definitely. The centre, that centre is a very, very important must. (Linda)

4.2.6 Suggestions for improving services

A common theme in suggestions for improving services was needing someone 'to bat for you' or 'run with the ball for you'. Participants wanted to feel that there was someone on their side who would give them

information, steer them in the direction of appropriate services and respond with practical and emotional support when this was needed.

It's the same kind of problems that are emerging again, lack of foresighted attention, knowing who to go to, somebody picking the ball up and running with it for you...You have to rely on people, you know, going round and dropping bits of information. There's all sorts of things there, but how do you find out about them? And I think that's the real need, is to understand this is a person that needs help, needs guiding, 'Have you done this, have you done that, do you realise this?' And whether they point you, send you off to subgroups that deal with social services and medical points and this, that and the other, and act as a sort of central point of reference, to help you find the right things or to know and understand what your rights are. I think there's a lot of assumptions that they make, particularly with people like social services, that you know what you're supposed to know and you know as much as they do about it and you don't. (Ken)

Participants wanted there to be a proactive reaching out to them by services, rather than them having to fall upon information by chance or do battle to obtain services:

I think when people take in somebody into their household with dementia or Alzheimer's or what have you, there should be somebody, there should be some sort of medical notes going on their file, saying for people to come out, because you've got so much to adapt to when you first take somebody on like that. You haven't got the time to be thinking about 'Oh, there's this organisation', and all this and that. There should be a thing where a package comes to you, or just support... I didn't know what respite was...Nobody came to me. I had six months, nobody came to me. So that's the big thing that I would say, that doctors should be made aware straight away they've come into a family. (Linda)

Participants wanted to feel that professionals and service providers understood their experience and engaged with them at a human level:

Obviously, they need to listen to what it is really like from somebody that's involved in it first-hand. I know it's difficult for people and a lot of things are done on research and statistics, but the most important people are the ones that are out there doing it and you can't get a more truthful portrayal of what it is truly like than from somebody that's involved with it at this point in time. It's been, for us, totally life changing, the last three or four years, you know, dreadful illness and, as they say, you know, in the papers, it's going to get worse in years to come and, you know, these people have got to sit up and listen. (Linda)

4.3 *The implementation phase*

4.3.1 Feedback and transition into implementation

The research element of the project was co-ordinated by a local team comprising the research lead, the commissioning lead for adult social care services (the statutory sector LPA contact), a representative from the voluntary sector LPA, a co-researcher and the Service User Development Worker from the Birmingham and Solihull Mental Health Foundation Trust. As the initial findings emerged, this group began to consider local dissemination and implementation. It was agreed that we needed to engage not only at a strategic level in relation to the development of local policies and resource allocation, but also at the level of frontline practitioners and clinicians and their operational managers in order to influence day-to-to practice. Furthermore this 'frontline engagement' needed to include primary and secondary care as well as the local authority and voluntary sector.

The timing of the research was opportune, as SMBC and Solihull PCT were in the process of reviewing their dementia strategy and were consulting on draft proposals. To link the research at a strategic level the commissioning lead took a short report regarding the research to the Healthier Community Board of the Local Strategic Partnership. To begin the engagement of frontline staff and their organisations it was also agreed that she would call a meeting of the multi-agency Dementia Strategy Group. This group had previously met to oversee improvements in services for people with dementia (although had not met for some time) and included operational and clinical representatives from health, social care and the voluntary sector. Involving this group in the organisation of the local stakeholder event would potentially help to ensure linkage with their current interests and also secure the interest of the representatives and their organisations in the dissemination and implementation process. Unfortunately it was not possible for this meeting to be arranged and so the planning of the event was effectively led by the local research team with the support of the implementation lead from the University. Subject to the agreement of the co-researchers (see below) it was agreed that the format would follow that of the event in Leicester.

A workshop had already been held with the co-researchers to discuss the emerging themes from the research findings and this contributed to the overall analysis. The OD lead attended a subsequent workshop with the co-researchers to agree which key themes to present at the stakeholder event. These themes were agreed as:

- Seeing the whole picture
- Doing battle with services
- Living well with dementia
- Change.

The structure of the event in Leicester, in which co-researchers worked with a co-facilitator to share research findings within small groups and then contribute to subsequent discussions, was discussed. The co-researchers liked this approach and were keen to actively participate.

At the end of this stage there was: interest from the Local Strategic Partnership; an identified body to coordinate dissemination and implementation (although this had not met to begin to take on this responsibility); a clear route into an existing local review of services; and support from the co-researchers and local team for the stakeholder event.

4.3.2 Negotiating interventions for change

As engagement at a strategic level was underway and the commissioning lead would be attending to 'represent' this work, the stakeholder event focused on bringing together frontline practitioners and clinicians, operational managers and voluntary sector organisations. To secure attendance from statutory sector agencies contact was made with the relevant director within the organisation and they were asked to nominate a number of representatives. Local patient, service user and carer representatives were also invited.

The event began with a brief overview of the research aims and methodology, and then participants were divided into mixed groups (i.e. health, social care, statutory and voluntary sector) who attended sessions run by a co-researcher with a member of the local research team. Participants learnt of the main research findings against the four key themes and were asked to address two questions in relation to these themes:

- Question 1: What are your initial reactions to the research findings? Are they what you expected? If not, what would you have expected?
- Question 2: What do you think has led to people having a good experience? What has led to them having a poorer experience?

The main responses in relation to these the four themes are summarised in Table 5.

Table 5. Local responses to the research findings

Theme	Responses
Seeing the whole picture	<p>Co-ordination and integration of services is vital and this needs to be across health and social care and the voluntary sector</p> <p>The 'course' of dementia in someone's life is predictable and so it should therefore be possible to plan appropriate responses</p>

	<p>Carers need support to develop skills and strength to cope</p> <p>Social workers should be more than a gate keeper</p> <p>Flexibility and looking at the 'whole person' and their 'whole family' are key to maintaining people in the community</p> <p>Listen to what people want – this may not be what we expect!</p> <p>Resources are limited</p>
Doing battle with services	<p>A directory of services so everyone would know what is available</p> <p>Training for staff, including GPs, is required so that they know what can be provided locally</p> <p>Information needs to be given pro-actively (and not just when asked for) and be in simple language</p> <p>Advice and navigation are also important</p> <p>'Stigma' and judgemental attitudes can determine if GP or Consultant offers a service</p>
Living well with dementia	<p>There is a lack of joining up and we need to see the big picture with all the services</p> <p>Not everyone has a carer</p> <p>A single point of access would make it easier to get support</p>
Change	<p>Participants were not surprised at the views of the older people and their carers but were still saddened to hear of so many difficult experiences</p> <p>The impact of a diagnosis is not the issue it's the battle which follows to get services and support</p> <p>Carers needs are very different to the needs of the person with dementia</p> <p>There seems to be the impression that people can just cope with dementia entering their lives, until a crisis, but by then it is sometimes too late for the right support</p> <p>Good experiences are related to: early referrals and information, effective networking across sectors, being listened to and a recognition that 'one size does not fit all'</p> <p>Poor experiences are related to: confusion about who to contact, lack of options, stigma and poor diagnosis</p>

	process and communication
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Each group was then allocated an aspect of the draft Solihull dementia strategy to consider in the light of the research findings. The aspects of the strategy discussed were 'Support for Carers', 'Community Support', 'Assessment and Entry to Services' and 'Awareness and Understanding of Dementia'. The event finished with the commissioning lead confirming how responses from the event would be incorporated within the consultation of the joint dementia strategy. Following the event the discussions were written up in the form of a report which was circulated to all attendees, and this included the reflection of the facilitators on their experience of running the sessions and their impressions of the responses by participants (Table 6).

Table 6. Reflections of the facilitators on the feedback event

Aspect	Facilitators Reflections
Response of participants to the 'process' of the event	<p>Each group approached the task with interest and enthusiasm</p> <p>They found the selected quotations very relevant which triggered some lively discussions about the importance of not seeing the older person in isolation but as part of a wider family or community unit</p> <p>People were inclined to look at the reasons why people have had to do battle with services and to look at what might help to overcome this difficulty</p> <p>It was encouraging and energising to see the high level of passion and commitment that delegates brought to discussion of services for older people with dementia</p> <p>The main issue to emerge was that most people around the table could not recall seeing previously the documents that were circulated. They were unsure about the basis for inclusion in consultation processes and felt that information had not been disseminated comprehensively. As delegates were not familiar with the strategy and related documents, it was not possible within the time available to make links between these and the research findings</p>
Response to findings	<p>There was a lot of discussion about the point at which help is needed and that often help and information would be useful earlier on, when people first begin to encounter difficulties with memory loss</p>

	<p>By the time the diagnosis is finally made and people are referred on to services, they have often struggled and found out the information they want for themselves</p> <p>No one said that they were surprised by the narratives from the research</p> <p>People involved in providing services expressed that they have had their own difficulties in accessing services even though they may have more of an insight into how services work</p> <p>They had concrete ideas about improvements that could be made in response to research participants' experiences, without additional investment of resources. However, there seemed to be no clear route for taking these ideas forward</p>
Further actions that could be taken	<p>The idea of a single point of contact was welcomed by some as a useful solution, but other people had experienced a similar system elsewhere and had heard of lengthy waits to get through to the number and receive a response</p>

Overall there was a positive interest and response to the research findings but many of the attendees did not remember having seen the draft dementia strategy previously, despite this having been publically circulated and made available on the council and PCT website. Thus whilst summary details were given on the day this lack of knowledge of the strategy did restrict the level of feedback that attendees could give and also caused some tension in relation to previous consultation and involvement with the strategy.

At the end of this stage we had an initial response to the findings from a wide stakeholder group and considerable interest in being part of the next steps in improving services.

4.3.3 Taking actions

In relation to strategic actions, the partnership structures have been changed in Solihull to reflect the evolving health commissioning bodies and the need to provide more integrated pathways across primary and secondary care and between health and social care services. The Commissioning Lead has arranged for the findings of the research to be circulated to the members of a Dementia Task and Finish Group that has been developed as part of the Frailty Board, and the senior commissioning representatives on the group will be reflecting on these at their next meeting. In the meantime, the research has been used to secure funding to

develop three key initiatives corresponding to the findings about early diagnosis, better information and informal support. These initiatives will be delivered by the voluntary LPA and include: dementia advisors working with GPs in their practices, a new dementia cafe (with more than 30 people attending the first cafe) and increased dementia support worker capacity. The Commissioning Lead described the research as a 'really good piece of work that validated what was in our draft dementia strategy'. The mental health trust also considered the findings of the research as part of a review of mental health services for older people.

In relation to dissemination and action on the frontline, two events were held for staff working within the acute hospital. The main themes from the research were presented, with supporting quotes being read out by two of the co-researchers. These events were well attended by over 50 staff representing medical, nursing and therapy disciplines but it is not clear what subsequent action has been taken by the Trust. The local voluntary partner is keen to continue with the co-research model in relation to service evaluation, but is concerned about the impact of delays in diagnosis on people's ability to participate – 'people with dementia can only have a voice if the dementia is diagnosed early'.

The co-researchers were keen to see improvements in practice in response to the findings and were willing to be part of the change process. They were initially disappointed when there seemed to be no tangible developments from the stakeholder meeting. There appeared to be a tension between the concrete and immediate changes desired by the co-researchers and the more planned and phased response of statutory agencies. The latter needed to work within bureaucratic decision making systems, combine multiple information sources as part of wider consultations and simultaneously manage multiple priorities. All of these factors slowed down their ability to act, although they may lead to a more coordinated and comprehensive response. This difference in the desired and actual pace of response reflected the experiences of the research participants in accessing services.

At the end of the research project the dissemination and implementation of findings were still in progress, but the additional funding secured by the commissioner for adult social care services gave the potential for improvement in services.

5 Older people from BME communities (Leicester)

5.1 Background and context

5.1.1 The local area

Leicester is a medium sized city with a population of approximately 289,000 (2006 mid-year estimate); a further 441,000 people live in the wider Leicester urban area. Leicester is one of the most ethnically diverse cities in England, with approximately 40% of the population from a BME group (see Table 7). People of South Asian origin constitute the largest ethnic minority group (31%), the majority of whom are Indian, with smaller Afro-Caribbean, Bangladeshi, Pakistani, Somali and Chinese communities. In Leicestershire, BME groups account for 11.1% of the county's population, and live predominantly in areas closer to the City Centre in the boroughs of Charnwood, Oadby and Wigston.

Table 7. Ethnicity profile of Leicester's population

Ethnic group	% total Leicester population
White	60%
Asian or Asian British	31%
• <i>Indian</i>	• 28%
• <i>Pakistani</i>	• 2%
• <i>Bangladeshi</i>	• 1%
Black or Black British	8%
• <i>Caribbean</i>	• 4%
• <i>Somali</i>	• 3%
• <i>Other African</i>	• 1%
Chinese	0.5%
Other	0.5%

5.1.2 The study in Leicester

The LPAs in Leicester were Age UK Leicester Shire and Rutland (voluntary) and Leicester City Council (statutory). Locally, Age UK has two active and

well-established forums for BME elders, covering the city and county respectively. A group of eight older people were recruited through these forums to be co-researchers and the two forum coordinators from Age UK played a central role in supporting the recruitment, training and ongoing support of the group. More information about the co-researchers can be found in Table 8 below.

Table 8. The Leicester co-researchers

Name	Gender	Age	Ethnic group	Main experience of hospital/transition
Balbir	F	61	British Asian	Direct experience as a service user
Balubhai	M	80	British Asian	Experience of supporting friends and community members in hospital
Jitendra	M	82	British Asian	Direct experience as a carer
Kailash	M	74	British Asian	Direct experience as a service user
Ranjan	F	72	British Asian	Experience of supporting family and friends in hospital
Rasik	M	73	British Asian	Direct experience as a service user
Saroj	F	66	British Asian	Experience working as a interpreter in hospital for many years
Tad	M	63	Polish	Direct experience as a service user

In consultation with LPAs, the process of going into and leaving hospital was selected as the main focus. A key factor driving this choice was that Leicester Council's health scrutiny committee had, in late 2009, initiated a review of discharge planning arrangements for patients leaving Leicester hospitals. This project offered an opportunity to supplement organisational data with more in-depth insights into user and carers' experiences of coming home from hospital. As time progressed, it became evident that the transitions research linked into a number of local projects, including major programmes of work to engage and improve hospital services for BME groups and to redesign the pathway for frail older people. Given this, the

research team worked closely with representatives from University Hospitals Leicester and Leicester PCT, in addition to the partner agencies.

5.1.3 Participant characteristics

Participants were recruited by three primary means: information circulated by Age UK and other local voluntary organisations, visits by the research lead and co-researchers to day centres and lunch clubs, and the informal networks of the co-researchers themselves. Additionally, the research lead was directly contacted by a specialist nurse for travelling families at Leicester City PCT which led to the recruitment of a group of women from the gypsy-traveller community. These women were interviewed collectively – and only once – in a focus group session, with the specialist nurse present.

A total of 24 people shared their experiences for the research, and 19 were followed up in a second interview (Table 9). Ten participants were interviewed in community languages, either Gujarati (n=9) or Punjabi (n=1). These interviews were led by co-researchers who spoke the relevant language, and were subsequently translated into English. The majority of participants shared an experience which was triggered by an emergency admission; reasons for admission included heart attack, stroke, stomach pains, chest pains, severe diarrhoea and vomiting, fall and exacerbation of an existing medical condition.

Table 9. Leicester participant characteristics

Name*	Age at first interview	Gender	Ethnicity	Service user or carer
Padma	63 years	Female	Asian/Asian British	Service user
Gulam	76 years	Male	Asian/Asian British	Carer
Alice	67 years	Female	Black/Black British	Service user
Gurnam	74 years	Male	Asian/Asian British	Service user
Kishor	63 years	Male	Asian/Asian British	Carer
Mahendra	67 years	Male	Asian/Asian British	Service user
Nayna	71 years	Female	Asian/Asian British	Service user
Zulekha	70 years	Female	Asian/Asian British	Service user
Meena	76 years	Female	Asian/Asian British	Service user
Nisha	43 years	Female	Asian/Asian British	Carer
Mukesh	79 years	Male	Asian/Asian British	Service user
Anisa	63 years	Female	Asian/Asian British	Service user
Nilesh	76 years	Male	Asian/Asian British	Carer
Mira	69 years	Female	Asian/Asian British	Service user
Jagjeet	74 years	Male	Asian/Asian British	Service user
Prakash	72 years	Male	Asian/Asian British	Service user
Sayeeda	68 years	Female	Asian/Asian British	Service user
Inderjeet	71 years	Male	Asian/Asian British	Service user
Salma	50 years	Female	Asian/Asian British	Service user
Kaitlin	65 years	Female	Gypsy traveller	Service user
Penny	65 years	Female	Gypsy traveller	Service user
Josie	66 years	Female	Gypsy traveller	Service user
Lynne	64 years	Female	Gypsy traveller	Service user
Rose	57 years	Female	Gypsy traveller	Service user

* All names are pseudonyms

5.2 The research findings

Participants, especially service users, commented far more extensively about being in hospital and their experiences of the care they received during that time than any other aspect of their transitional journey. The findings relating to hospital experiences are presented under three key themes: interpersonal dimensions of care, communication and language barriers. Following this, experiences at points of transition, issues concerning home and social support and suggestions for improving services are reported.

5.2.1 Interpersonal dimensions of care

Good and bad experiences of hospital care were mainly described by people in terms of how they, or their friends and families, had been treated by hospital staff. Given the highly relational and often intimate character of nursing care, it is unsurprising that the majority of comments made about the nature and quality of interactions concerned nursing staff. Nonetheless, the findings indicate that patients' and carers' experiences were shaped by the contact they had with all staff groups including doctors, paramedics and non-clinical employees such as cleaners. People sometimes drew on examples about how they were treated to form or confirm perceptions about staff attitudes and values. For example, Rose noted that:

Nurses are very nice but the doctors are very sarcastic...They just come so blunt and walk away, you know what I mean? They know everything...It's like they've got authority over you because they're a doctor, you're only a pensioner. You're depending on them so they'll just see you when they want to, talk to you when they want to. That's how it's like. (Rose)

People wanted staff to recognise and treat them as an individual person. At issue was that fact that the hospital care could be cold, impersonal, even de-humanising:

Well, if the staff could treat us like individuals and if they could be more sympathetic to us. I know that what they're doing for patients is obviously correct, but the people who go in with patients, such as myself taking my wife into the hospital, instead of being totally indifferent, they could at least come, provide, well some little snacks for people who are there hours on end waiting...At least, ask if you're alright and reassure that help is on the way for your wife or husband, whoever, and be treated a bit more kindly, which did not happen at all. (Kishor)

Even small gestures by staff to see and connect with the 'person in the patient' – smiling, asking if the person was OK, using their name – could make a big difference to people's wellbeing and help them to cope with the experience of being in hospital. This was illustrated by Nayna, who

recounted a time when she had to undergo a somewhat unpleasant procedure:

The nurses was lovely nurses, there were four, five, you know. Smiling faces, and you feel like, thanks God. And you don't feel sorry for yourself, because they send you with a smile and that don't cost anything. (Nayna)

The image of good interpersonal care that emerged from the interviews contained emotional and physical aspects. On an emotional level, feelings of fear, worry and uncertainty were significant and common, especially at the early stages of the hospital stay. As Gurnam noted, when asked how he felt when he was being admitted into hospital:

Sometimes you get a little bit worried about, because when something is happening in your body, you get so many ideas. It may be something like cancer, maybe something, this or this or this. When you're getting sick, and something goes wrong, there are so many things coming in your mind. (Gurnam)

Three things emerged as playing an important role in helping people to cope with the emotional burden:

1. Having feelings *acknowledged and validated* – e.g. by staff showing empathy and compassion
2. Having feelings *responded to* – e.g. by staff providing reassurance that they were doing what they could to help
3. Having an opportunity to *share and express* feelings – e.g. by having somebody to talk to.

This last issue was discussed at length by Padma who was admitted into hospital with a major heart attack and subsequently underwent a triple bypass:

I've got a lovely husband...but some things you cannot talk to your family about. You want to speak to somebody outside them...I think if you've got that sort of thing, it would have been brilliant. [Interviewer: What did you want to talk about, what sorts of things?] How you feel. Sometimes there are certain things you can't tell family, because it's emotional and they're involved in it too, and you don't want to upset them. You don't want to get upset in front of them, because then they will get upset. (Padma)

In terms of the physical aspects of care, a number of people noted that the hospital had done a good job of 'fixing' whatever problem they had been admitted with, but there had been lack of attention to their general physical needs and wellbeing. In some cases, participants required but did not receive help with eating, using the toilet or having a wash, or they witnessed these needs being overlooked in other patients:

They didn't come and ask you – not me only, anybody – 'Why didn't you have a breakfast, is something wrong, you need to be fed or not?' They don't come and ask you, they just took the food away. If you can eat it, fine. If you can't – because one or two was quite ill there – nobody asked them for days. They came and took the food, but they didn't question you about why didn't you have it, whether you didn't like it, or what the reason was. (Nayna)

Not receiving help with basic personal and hygiene needs could diminish people's dignity and sense of self. Anisa described how she started experiencing urinary incontinence as a side effect of a medication she was given. She had to wait what seemed like an unreasonably long time to be washed and have her bed sheets changed, and felt that the nurses' response downplayed her feelings about being in a soiled bed:

And one day, I was wet, somebody didn't come about two hours, more than two hours. And I said to them, 'I can't control myself because of these tablets'. And, you see, I couldn't walk, so I couldn't go to the loo. So I had to change and everything, wash me and everything, but that took them too long, you know, to do those things. But then nurses, they say 'You worry too much, you know, relax'...So that was bit unhappy part for me. (Anisa)

This quote is illustrative of another central theme about the hospital experience, which can be broadly termed as 'helpfulness and responsiveness'. Participants valued staff anticipating their needs and proactively offering help (helpfulness), and responding to requests for assistance in a polite and timely manner (responsiveness). A range of experiences were shared, but many participants recalled a time when they felt hospital staff were rude or unhelpful, when they had been ignored or forgotten, or when they had needed to 'get shirty' in order for something to happen. The time taken for nurses to answer call buttons was a common complaint:

Sometimes when you press the buzzer, like me I had to press for it 'cos I couldn't get out of bed, it used to take them a long time, sometimes a long time to come. You've nearly wet yourself before they come. (Kaitlin)

One night I wanted to wee and I was ringing for the commode and when I couldn't get the commode, I had to pull a bath towel and fold it up and shove it between my legs so that it would absorb it and I thought I don't feel good about it. (Alice)

The most negative examples involved patients being told off, reprimanded or punished by a staff member. Meena described what happened after she had complained to a doctor about the way that a particular nurse was treating her:

And the nurse, do you know what she did to me? She just stopped speaking to me...What she'd do was, just say her hellos and give the medicine. The barest minimum, just covering her duty, you know...I thought, well, I had a word and she didn't like it. I spoke to the Gujarati doctor, he must have spoken to her, and then she just didn't speak with me anymore. (Meena)

5.2.2 Communication

Few participants talked about wanting active involvement in their care in the sense of making or sharing decisions with professionals. Yet there was a widespread expectation that patients and families should be kept informed about their health and the management of their care, given diagnoses, told about treatment options, and have their views respected in any decisions taken. Wanting to be listened to and understood was also frequently mentioned, and when this happened it evidently made people feel respected and cared for. Padma talked about how grateful she was to a doctor who listened to and tried to gently calm her fears about going into an MRI scanner:

I went in for an MRI scan where they put in you in the tunnel sort of thing for an hour and a quarter. I was very frightened, very frightened. The doctor was very good, very good. She says to me, 'Mrs [name], you're frightened'. I says, 'I will die in it, you know'...And she was so nice, she says to me, 'What I'll do, I'll give you the injection. If you feel like it, we'll do it. If you don't feel like it, we won't do it'. And as she knew, once she'd done the injection I would go in without fear. Probably she knew. She was so calm, she spent about 20 minutes with me to calm me down. (Padma)

Good communication and the reassurance it offered played a vital role in fostering trust between patients and professional caregivers. This point was made explicitly by Josie, in response to a question about services should be improved:

Just communication on the level that you're a person. [Interviewer: OK, say a bit more about that because that's an interesting point.] That you're a person, so they say, 'Well if you don't fully understand ask me I will explain to you' so that you're a...one to one, you can build up a trust, and a trust that works both ways. Because then you trust them and they trust you. (Josie)

Josie was one of many participants who felt uninformed or were told about developments in a way that was not understandable to them. Several people mentioned difficulties trying to get information about the progress of tests and investigations. Inderjeet and his wife talked about having to 'probe and ask' doctors to find out how his leg had been damaged (following a fall) and what had been done in response:

Inderjeet: We didn't immediately get told from the doctors what the problem is...

Wife: We had to probe and ask.

Inderjeet: The consultant told us after many days what had happened, what they had inserted into the leg and so on.

Some people suspected that their diagnosis had been known for some time before they were told about it. Gurnam recalled asking nurses what was wrong with him, after he had been admitted with vomiting and diarrhoea and a very high temperate. As he explained:

Sometimes when we do ask the nurse they don't tell. What happened during that period, my blood pressure was going very high, sometimes a hundred and ninety three, sometimes two hundred or something like that. So I was asking why this blood pressure is high? I was worried about this thing and I did ask them is it very serious or something like that? They told me it will be alright when you have a pacemaker.
(Gurnam)

It was only at the point of leaving hospital, when he was given a report summarising his care, that Gurman realised he'd had a heart blockage.

Our findings suggest that communication with carers was particularly poor. A good illustration of this problem was provided by Nilesh, who had been upset that the hospital had not contacted him about either the timing or the outcome of his wife's hernia operation:

My next door neighbour, she went there to visit and when she came back she said 'Oh dear, they're going to take you wife for her operation'. I said 'Nobody told us that'. And they took her to the theatre at nine o'clock and the operation finished on Monday morning at one o'clock. My daughter and I were worried about it, and we rang up several times to the ward but they don't bother to answer or anything...Then two o'clock in the morning I rang up, I said 'What's happening, why can't you inquire more, she has been having the operation for hours or something'. So the nurse she went to inquire and then she came back and told me 'Oh she has been transferred to the intensive care unit'. (Nilesh)

5.2.3 Language barriers

The most dominant theme within the Leicester findings was that of language barriers, especially for people who spoke limited or no English. In hospital, people who did not speak English were neither able to understand what was happening to them, nor provide information that might be important to the safe and effective delivery of their care (e.g. describing symptoms, sharing which medications they were taking). Language barriers also significantly limited interactions with staff and other patients, and all but eliminated opportunities for people to be involved in their care, even in

the most basic ways such as choosing meals. This often left people feeling vulnerable and – at worst – afraid. This was summarised by Nayna who noted that:

It's scary to go, to leave your home, you've never done that. And then suddenly, when you've got a language barrier, we can only say 'thank you' and 'yes' or 'no'. And you don't know what you are saying to yes and what you are saying no to. (Nayna)

There was a sense amongst many participants – not just those who were directly affected by language barriers – that people who did not speak English received a poorer level of care than those who did:

The people who speak the language they have no problem, but the people who don't speak the language, they have got a big problem. They can't say anything, they can't tell what is happening. Suppose if people don't know the language, now suppose they have to go to the loo. They can't say anything, just shouting like. Maybe they know just one word: nurse or doctor...People who can speak the language they can explain what is happening. (Gurnam)

Closer analysis of the findings suggests that two factors underpinned this view. The first is the practical issue, described above, of staff and patients not being able to understand one another. It appeared that, in some cases, staff and/or patients eventually gave up trying to communicate or limited their communication to the barest minimum:

There were many times when Mum would prefer to have asked for some sort of help or assistance and she has said herself that she ignored her own needs and that at times when she would have preferred to have asked a nurse for help to perhaps get to the toilet or perhaps to let someone know that she was even feeling quite nauseous or dizzy, that she didn't really feel inclined to let anyone know. (Nisha)

Given the importance placed on the interpersonal elements of care, it is easy to understand why this withdrawal or isolation from everyday interaction could leave patients dissatisfied with the care they received.

The second factor is a cultural dimension, and concerns the way that staff were seen to view and treat people who did not speak English. A number of participants described staff interactions with non-English speaking patients as being less friendly and more aggressive and impatient, and some were left with the impression that these patients were seen as unduly time-consuming or bothersome. Lynne, a participant from the gypsy-traveller community, recalled an incident involving a patient of Asian origin who spoke very little English and was trying to communicate that she was vegetarian:

As far as I could make out, that's what she was trying to tell them. And [the person serving food], honest, now she was only giving the

dinners out, the abuse she gave that woman. And I'm laid there with a mask on, couldn't breathe and I felt like getting out of the bed. Anyway off she went and the poor woman is trying to explain. She come with a yoghurt, she banged it on the table, she said 'Well have that or nothing', and then left that woman there. And she was just, nobody was trying to help her. Nobody could understand her. And I said 'If I could just get off this bed' but I couldn't. I couldn't do nowt about it 'cos I was stuck to the bed. But honest to God, that's just how they treat us, like pigs. (Lynne)

Padma described how upsetting it was when a doctor told her she needed a triple heart bypass in what she felt was an insensitive way. His behaviour, she suspected, was due to an assumption that she had limited language skills given her South Asian ethnicity. Padma, a fluent English speaker, explained:

He [the doctor] says, 'I can't do anything, you've got to have a bypass', that's all he said, nothing. And then says, 'Move on the bed'. I went there, they took the tube out. And, one of the nurses with me, she says to me, 'What's wrong?' I said, 'How he spoke, that's not the right way to speak to people, he never explained to me.' For him, I was just cattle, something like that, and that's not right...He thought that being me Asian, I couldn't understand what he's saying. But I understood...OK, you are pressed for time, you've got to do so many [consultations], I can understand that. But still you're talking to humans, we are not animals. (Padma)

The extensive comments made about the problems of language barriers raises a question about the availability of translators within hospital. The hospitals covered by our research did have translators, but participants' reported that they were only available sporadically, if at all. A wide variety of people had been informally involved in translating for patients: from staff in different parts of the hospital known to speak the relevant language, to family members and fellow patients. Sayeeda received help from another patient:

I did have a neighbour, an auntie who was very nice, a Muslim lady, and she said 'Since you don't know the language if there's any problem, just let me know and I'll explain'...And I said to her 'Will you please help, I'm not understanding this and this', especially around the time of the operation. The nurse gave me clothes to wear, and I wondered why she had left me the clothes, so she [the Muslim patient] asked for me about the clothes and we were told about the operation that day. I thought the doctors asked me to go home. (Sayeeda)

Participants didn't necessarily see the involvement of informal translators as a problem *per se*, and many were grateful for their help. However, the limited availability of professional translators did present problems, above all because a translator was often unavailable at the particular time that

they were needed, so opportunities for clinical staff to keep patients informed or involve them in their care were lost or substantially delayed.

5.2.4 Points of transition

During admission into hospital, and the earliest stages of the care pathway, fear and worry were universal emotions amongst participants. However, there were important differences between patients and carers in terms of the feelings they had about discharge. Patients were generally relieved to be leaving hospital, whereas carers were more worried about how they were going to cope once their family member returned home. Discharge was evidently a far more fraught time for carers than it was for patients themselves.

The accounts shared indicate that participants were given very little, if any, advance notification of transfers or discharge. Often, people were told about discharge the day before it took place. Nilesh's experience was typical:

On Wednesday, we went in the evening and nurse said 'Oh probably your wife will be discharged tomorrow'...I said 'How is she going to come home?' because I don't drive, I haven't got a car or anything. The nurse said 'Oh she will be transported by ambulance' and I said 'OK'. (Nilesh)

When Nilesh returned to the hospital the next day, no transport had been organised as promised and the staff member on duty was not willing to make the necessary arrangements. A neighbour who had accompanied him to the hospital was able to help out, but because of child seats in the back of her car Nilesh had to take the bus home rather than accompany his wife – a situation he felt angry and embarrassed about.

Not knowing when discharge was expected to take place made it very difficult for families to make their own practical preparations for the patient's return home. The fact that many participants felt like discharge had been 'sprung' on them indicates how little they were involved in planning this aspect of their care. This is a point that Nisha touched upon during interview:

It felt like the decision had been made – that Mum would be discharged at a certain point and it all seemed very abrupt when the decision is made. It's almost as if the care is taking place and the medical reviews are happening, but then suddenly someone has decided that the person is well...It's a shock to the family as well, because the family are led to believe that the person is quite ill and then suddenly they're not supposed to be ill. (Nisha)

A number of participants made comments which suggested that discharge would have been a far more positive experience if they and their families had been kept regularly informed about what was happening at this time and informed of any changes to arrangements.

A major theme at points of transition, especially discharge, was delays and waiting. Several people had their discharge delayed by one or more days, usually because they were either not considered medically fit enough to return home or were waiting for home adaptations or domiciliary care packages to be put in place. Gulam's case was an extreme one – he waited for almost 6 months for adaptations to be made and an electric bed to be provided before his wife could return home. Gulam felt excluded from decisions about his wife's care, and was particularly distressed when she was transferred to a care home without him being consulted about this first. He explained:

They kept her in hospital for two months and told us to leave when they needed the bed. We went into a nursing home and there, it was the kind of place where they wouldn't even change her pants when she had urinated. They did everything for her whilst she was seated at the wheelchair, even feeding. (Gulam)

Delays on the day of discharge itself also occurred frequently, the main causes of which were waiting for transport and/or medicines. These delays left patients in a 'limbo' state: stuck at a halfway point between the hospital and their onward destination, unclear about who was responsible for them and their care at that time.

It was during these limbo periods that slippages in care often happened and people frequently felt overlooked or neglected. Kishor spent around 4 hours in the middle of the night waiting for transport to transfer his wife to another hospital. He explained:

I had to ask them a few times when she's going to be taken to [the second hospital]. They said, we don't know, we're running late, the usual excuses. I mean, they do this all the time so they know what to say. But nothing that would satisfy a person like me that, you know, that this is going to be taken care of soon, they're on the way, or would you like a cup of tea or a drink... And I was very disappointed, actually. Is this how they treat people, you know, especially in a distress situation...The least they could do is make people like us comfortable and just offer us a drink. We didn't expect anything big but couple of biscuits and things like that. (Kishor)

Another key theme was the provision of information on discharge from hospital. Discharge information was a major unmet need, especially for carers who were looking for information to provide some reassurance and support at this anxious time:

What they put in the discharge letter, nothing was explained to me, what she should take at home, nothing was explained, you see. We brought her home and, at that time I was on my own and I was wondering how was I going to manage her. (Nilesh)

Where information was sought, it was usually about: 1) what to do back at home, for example how to manage care effectively at home, when to resume normal activities, what to do if symptoms worsened; and 2) what services would be provided after discharge and/or how could services be accessed if needed. When information was provided it was always valued and appreciated:

They told me what to do, not to move and not to sleep on the left hand side or something like that...Then they gave me the book.

[Interviewer: Was that information helpful to you?] Yes it was very helpful to me that they gave me the book to know what to do, like a pacemaker book and the sort of instructions they gave me. (Gurnam)

Unfortunately, Padma's was a far more common experience: when asked what she was told on leaving hospital she replied 'Nothing, just given my medicine bag, nobody told me anything.'

A final important point is that experiences of transitional care – such as reablement and rehabilitation – were very positive, and these were among the most highly rated services mentioned during the interviews. These services helped to smooth processes of transition by acting as a bridging point and providing structured support throughout the period of change and readjustment. An especially beneficial aspect was that they worked in a holistic way, supporting the 'whole person' their family, rather than just focusing on immediate physical needs:

The reablement team were able to take responsibility for Mum's move back to home, because it was – being a single carer and the main carer for Mum – it was quite a stressful period. And I'd say that the reablement team were able to relieve and take away some of that stress. They provided what seemed to be not just sort of practical care but emotional support as well for myself. And through the fact that they could afford the sort of time that is needed to help people and particularly the carer, to adjust, to help the adjustment period for the carer and the person who has just come out of hospital. (Nisha)

Nisha noted how members of the reablement team made special effort to communicate with and involve her mother – who has dementia – in the care process. She described the period during which reablement was provided as 'One of the most valuable times in terms of Mum being able to open up and communicate her own needs.'

5.2.5 Home and social support

Throughout the interviews, participants emphasised the value of family, friends and community networks. Many people talked about how important family relationships were to them and our findings suggest a strong connection between family situation and perceived wellbeing amongst this group. This is illustrated by a comment made by Nayna:

I will tell you something, everything comes from family, you know. If you've got a good family, I think it makes so much difference. (Nayna)

Meeting with friends and taking part in community life was held to be important by people irrespective of whether they lived alone, with a spouse or with their extended family. This suggests that wider social contact is valued and valuable whatever the living situation.

There was a widespread hope and expectation amongst patients that, after leaving hospital, practical help in the home would be provided by their family. Indeed, several people talked about not having a need for formal support services, such as domiciliary care, because they lived with or close to family members. At the same time, it appeared that services sometimes made assumptions about the families being willing and able to provide support, especially for people of South Asian origin. Padma told us that 'Most of the people think Asian people, they look after each other.' Previous studies have also found evidence of a taken for granted view that people from Asian backgrounds are supported by family and community networks, and therefore do not require services (92;93).

Most participants recalled their need for home care being established on the basis of an informal discussion shortly before the day of discharge (e.g. being asked 'Can you cope at home?') rather than through formal assessments. For Nayna, the risk with this approach was that it wouldn't capture the full range of needs and leave people coping at home without adequate support:

When they send you home, they have to think, how ill is the person, what can the family do, what can't the family do, how are they [the family] going to give her help, what are we [social services] going to give....Because they don't come and see you, they just, whatever you say on the phone, or whatever the family will say on the phone, they never come and see how much help you need or what is wrong with you. (Nayna)

Carers also identified shortcomings in the way that support was assessed, above all that decisions had been taken without them or other family members being consulted. In effect: while patients wanted their family to help out, and services sometimes assumed this would be the case, families themselves were not always given the opportunity to say whether they could cope without additional external input.

Many families did appear to be coping well, and this was especially true where extended families were living together in the same house. Others were finding it more difficult; for example, Nilesh described how he felt 'abandoned' by services when his wife left hospital following a major hernia operation. He explained:

We didn't get any help, so we were on our own. Luckily my family members, I mean, my daughter stayed for a week and at least tried to

help and give [my wife] some support. Then another week, another daughter came...We've had no support of any kind, only the support of family members. They come from a long distance here to look after Mum. This is the thing, they [services] expect us to, you see. (Nilesh)

A further issue was that informal support networks of family and friends were rarely in a position to provide 24/7 support. This could leave people feeling anxious and insecure, a problem that particularly affected carers like Nilesh.

Among participants who were receiving home care, experiences were extremely variable. The most positive experience was shared by Nayna, who had used a personal budget to hire her own careworker with whom she had developed a close relationship. At the other end of the spectrum, Nisha and Gulam (both carers) expressed considerable dissatisfaction with the quality of the home care that was being provided by local agencies:

Well the official written time is seven thirty am but sometimes they come late in the mornings...They tend to take their time getting here, they come over, after breakfast, and having cleaned the bathrooms, leave promptly. [Interviewer: So it's a bit rushed?] It takes them twenty five minutes, and well, it should be forty five minutes, for both carers. (Gulam)

We have had carers from the present agency who have physically held Mum's wrist, have sort of pulled her wrists and been physically – on a mild form – abusive and verbally abusive as well. There have been carers that have tried to humiliate Mum in the shower room and so I had a dreadful time of it. (Nisha)

In these cases, the shortcomings in support services were actually adding to the stress that carers were experiencing rather than helping them to cope more effectively.

5.2.6 Suggestions for improving services

Four main recommendations for improving services for older people were made by participants:

- Equip staff for clear, patient-centred communication
- Ensure that patients and families are treated kindly and compassionately, at every stage of their care
- Pay more attention to the needs of carers
- Enhance information sharing and coordination, especially between hospitals and social care, and hospitals and general practice.

Improved communication was by far the most popular recommendation and included a number of specific suggestions including: sharing information with patients using non-technical language; increased availability of

translators in hospital; and not rushing interactions so that information could be properly explained and understood. For example, we were told:

When you can't read and write you have to have everything explained to you so they should spend a bit more time with you to explain things. I know they're in, everybody's in a rush, but sometimes they rush just a little bit too much. So they've got to slow down a little bit, listen to the patient a bit more and explain. (Josie)

The second recommendation reflects that crucial role that interactions with staff have in shaping experiences of using health and social care services. The request was for staff to show more compassion and kindness to patients and families during what can often be anxious and uncertain times.

I hope they, you know, change their attitude and become a bit more friendly and try and comfort, not just the patients, but the people who are with the patients, the carers. Make them comfortable and reassure them. It doesn't take long, it doesn't cost much. (Kishor)

Kishor's comments are also illustrative of the third recommendation made: that services should recognise carers as individuals who are affected by the care process and, therefore, entitled to be informed about and involved in it. Specific suggestions ranged from the relatively simple: keep carers up to date with any major developments while their family member is in hospital, to the more complex: having trained mediators who could facilitate communication and collaborative decision-making between patients, family members and professionals. Coordination between professionals and services was the final area where improvements were felt to be needed, to help ensure that transitions between services and settings are as smooth as possible. Participants did not generally offer specific suggestions, but what emerged was an image of services working together in a more integrated and joined up way. On this issue, we heard from Nilesh that he wanted:

A change in the procedures...There should be some sort of liaison between the hospital, GP service and community, the social services. (Nilesh)

5.3 The implementation phase

5.3.1 Feedback and transition into implementation

During the project there had been changes in the role of the senior manager within the City Council who was the statutory LPA contact and also in the way that health and social care services structured their partnership working. Towards the end of the research phase, a meeting was held with the leads from the statutory and voluntary sector LPAs and a representative from the acute trust to confirm that the research project was ready to move on to dissemination and implementation and agree how this transition could best be approached. The outcome was an agreement that the initial findings

be presented to an inter-agency Transfers of Care Group which oversaw local developments to improve hospital discharge. The Group had commissioning and provider representatives from health and social care and covered Leicester City, Leicestershire and the Rutland area. It therefore covered the main aspects of the health and social care economy that would be required to implement change and was well placed to co-ordinate local dissemination and implementation.

A slot at the Transfers of Care Group was arranged and, while the time given to discussing the research at the meeting was limited, the group expressed its support for an initial dissemination event and suggested stakeholders that should be invited. The group also identified a Programme Director based at Leicester PCT, who was leading a service redesign of the frail older people's pathway, as the main contact. This pathway was to work across health and social care and consider both admission and discharge from hospital and so connected well with the focus of the research.

At this stage we recognised that the co-researchers might need to shift away from a more 'protected' research role (in which they engaged with individual participants and their families) to a more 'public' change agent role (in which they would be interacting with groups of professional stakeholders from statutory and voluntary organisations). This would require not only a different skill set – e.g. presenting findings, explaining the analysis and discussing potential ways forward – but also the confidence that their experiences and opinions mattered. At an initial workshop, the co-researchers and members of the research team reflected on this transition and began to plan an event for local stakeholders. Above all, they were keen that findings were used to make positive changes but were daunted at the prospect of presenting to a large audience. With this in mind, the OD and research lead devised a structure for the event in which the findings would be presented in small groups by co-researchers and a 'professional' member of the research team or representative from the local advisory group. A subsequent workshop was held at which this approach was discussed with the co-researchers and key themes to be presented at the event were identified. The key themes chosen were: being in hospital, points of transition/going home, issues for carers and communication and the co-researchers selected quotes that illustrated these themes which would be read out on the day. This process strengthened the 'theming' of the findings and helped the co-researchers to make the transition to their new role.

At the end of this stage we had therefore successfully undergone three important transitions: to the new role of the co-researchers, a new lead individual and to a new strategic group to lead on implementation.

5.3.2 Negotiating interventions for change

The PCT Programme Director identified key representatives from statutory health and social care organisations to be invited to the event, and this was

supplemented by discussions with the LPA contacts regarding appropriate voluntary organisations and patient, service user and carer representative bodies.

Following a plenary presentation of overall findings, attendees were allocated to small groups and circulated around four rooms in which they were presented with more detailed findings on each of the research themes. The groups progressively addressed a series of questions in relation to that theme, with subsequent groups adding to the views given by previous groups. The questions were designed to enable participants to express their initial responses and then build towards the outcomes that Leicester would seek to provide for older people in transition:

- Question 1: What are your initial reactions to the research findings? Are they what you expected? If not, how do they differ?
- Question 2: What factors do you think account for good experiences? What account for poorer experiences?
- Question 3: What would we want people's experience to be in relation to this aspect of the care pathway?
- Question 4: What would we have to change to achieve this desired experience? How could this be done and by whom? How should the research findings have a part in this?

As planned, these groups were co-facilitated by a member of the research team/local advisory group and co-researchers, and involved a combination of summary findings and detailed illustrative quotations. This approach enabled participants to engage with the experiences of the older people who had participated in the research, which generated considerable enthusiasm both for wider dissemination and action to be taken to improve older people's experiences in future. Feedback was positive both in terms of the process used and also the potential of the findings to improve practice (see Table 10). The co-researchers were also positive about their individual experiences of taking part and also the potential for them to have a further role in leading change.

Table 10. Feedback from the stakeholder event

Aspect of Event	Comments
Process	<p>'Very good way of disseminating findings in an interactive way, also enabling a link with the local work addressing the issues.'</p> <p>'Good opportunity to share experiences and the contribution from different ethnic groups was fabulous.'</p> <p>'The moving around the groups was a bit of a challenge (time management) but it was do-able enough to constitute a workable method – I wouldn't change it.'</p>
Potential of Findings	<p>'The feedback will be invaluable in planning future work.'</p> <p>'We will use feedback in planning future areas of work and in discussions with UHL. In addition we will revisit Home from Hospital discharge scheme.'</p>
Future dissemination and implementation activities	<p>'I would suggest further firming up the link with practice by putting any other dissemination within a practice event rather than a stand-alone event, e.g. if there was a day workshop on the care pathway project.'</p> <p>'This would be excellent as a short presentation to nurses on the wards and as the basis for an induction session for doctors and nurses – even final year pre-registration nurses and final year medical students, especially based on the personal statements.'</p> <p>'Pictorial representation for non-English speakers (particularly to support the proposed hourly rounds of nurses).'</p>

It was planned that participants would respond in relation to the individual themes that were being presented, but in practice they tended to make more general responses to the findings as a whole as well as sharing their previous experiences. So the feedback was summarised against the four questions and not the presented themes (Table 11).

Table 11. Summary of small group discussions

Question	Response
Initial reaction to findings	<p>Attendees were expecting to hear mixed experiences and felt that they mirrored other evaluations and complaints</p> <p>Strong commitment from all stakeholders to improving experiences</p> <p>It was thought the issues raised would be similar for other communities (including African-Caribbean and Chinese)</p> <p>Lack of communication is key issue throughout</p>
Underlying causes of good experiences	<p>A multi-disciplinary approach improves experience at all stages</p> <p>Reablement services involve carers in assessment and assess people in their own homes</p>
Underlying causes of poor experiences	<p>Lack of clarity in processes and roles</p> <p>Hospital staff are not aware of other agencies roles and contact details</p> <p>Changes in referral procedures and eligibility criteria and differences between city and county</p> <p>Managers are not ensuring that staff consistently meet quality standards</p> <p>Some staff do not have sufficient respect for patients</p> <p>Pressure to reduce length of stay makes it difficult to focus on relational aspects of care</p> <p>Some patients will downplay their support needs to avoid delay in discharge</p> <p>Too many strategies divert staff from the basics</p> <p>Community follow up by primary care is not always sufficient</p>
Desired outcomes	<p>To have been cared for well and been shown compassion</p> <p>Staff and managers recognise good work and identify and share best practice</p> <p>Process to be coordinated and flowing – no gaps</p> <p>Always a clear first point of contact about issues/concerns</p> <p>Communication meets individual language needs – staff</p>

	<p>can recognise the need for language support</p> <p>Patients and carers involved throughout discharge planning</p> <p>Being clear about what can and cannot be provided</p>
Potential actions	<p>Start discharge planning before admission for non-emergency and on admission for emergency admissions.</p> <p>Identify who is 'nurse in charge' of ward and who is key-worker for discharge arrangements</p> <p>Have a named individual/team responsible for discharge planning on all wards</p> <p>Develop competence and confidence of hospital staff in understanding different cultures and communication approaches</p> <p>Greater availability of interpreters and for this service to be co-ordinated</p> <p>Better information for hospital staff on role of community and social care services and how to access them</p> <p>Improve information for patients and families on what support is available and how to access it</p> <p>Address issue of people who do not meet criteria for statutory social care; who will provide lower level support?</p> <p>Discharge planning process to successfully link with and engage GPs</p>

At the end of this stage, engagement with the local health and social care community had made a positive start, responsibility for further dissemination and taking action had been accepted by local agencies with an identified lead, and there was enthusiasm for maintaining active involvement of the co-researchers.

5.3.3 Taking actions

Strategic commissioning actions were to be coordinated by the Programme Director for the redesign of the frail older person's pathway. The findings were fed into the redesign project along with the findings from local consultations and analyses. The Programme Director then left her post and responsibility for the pathway was handed to other senior representatives within the area – despite the research team's best endeavours it was not possible to engage with them to support further reflection on the findings and understand how they could be used within the pathway development.

At this strategic partnership level there was a sense therefore that considerable redesign work was already underway and that the research findings were best used to inform and underpin existing redevelopments, rather than new initiatives be established. This was in many ways a sensible and appropriate response; however, from the research team's perspective, it was not explicit how the experiences of the older people within the research were used and the extent to which the co-researcher team would be involved.

In relation to organisational delivery and change on the front line, there have been more tangible impacts. The positive experiences of reablement shared by participants in the research have been used to support the expansion of the service so that it can work with all people who are being discharged from hospital and the Local Authority has developed the role of health and social care co-ordinators to provide a better linkage between in-patient and community services. A number of links with the acute trust have been developed and through these the findings have influenced and added momentum to a various initiatives aimed at improving patients' experiences and enhancing the patient's voice. These include:

- The re-introduction of the Matron role to oversee quality within each ward, and two hourly 'well-being checks' proactively asking patients about their current condition and identifying if any care is required
- A review of hospital interpreting services, with a view to increasing the availability of interpreters and range of languages covered
- The development of a Patient Feedback Volunteer role, with service users and local community members recruited to support patients giving feedback about their hospital experience. This will include bi-lingual volunteers to engage patients who are unable or are less comfortable completing feedback surveys in English. This peer-to-peer approach draws directly on the co-research model used for the study.

The findings are also being used as part of an initiative within social services seeking to emphasise to staff the importance of the relational aspect of their work and by Age UK for inducting new recruits about the importance of a personalised approach to providing support. The statutory LPA lead has emphasised the impact of the co-researcher model both to the research and to the dissemination and implementation – 'in the current financial climate it would have been easy for people to dismiss experiential research but this hasn't happened...co-researchers feeding back personal messages made it much harder for people to dismiss'. The findings were also seen as important – 'very relevant in terms of our local priorities and helped us to focus on what is important'.

There was also impact in relation to the empowerment aspect of action research. The two Age UK BME forums from which the co-researchers were recruited decided to hold a meeting to which representatives from key

statutory agencies were invited and asked to report what actions they had taken or were planning to take in light of the research findings. The meeting was attended by representatives from the Local Authority and the Acute Trust and enabled the co-researchers and other community members to hold providers to account for listening to and learning from older people's experiences.

6 Older people in an area with a proportionally small older population (Manchester)

6.1 Background and context

6.1.1 The local area

Manchester is a large city with a population of 498,800. It lies within the larger conurbation of greater Manchester which has a population around 2.6 million. Manchester has a relatively small older population compared with the UK overall (Table 12).

Table 12. Percentage of older people living in Manchester compared to UK

	Manchester % of population	UK % of population
Over 65	10.1%	16.6%
Over 75	5.0%	7.9%
Over 85	1.5%	2.3%

Manchester's population has been growing since the start of the decade, with an increase of 17.9% since the 2001 census. In 2009, the ethnic breakdown of the population was 77.3% white groups; 3.3% mixed ethnicity; 4.4% black; 9.9% Asian; 1.8% Chinese; and 3.4% other ethnic groups. Manchester is the fourth most deprived local authority in England, behind Liverpool, Hackney and Newham.

6.1.2 The study in Manchester

The LPAs in Manchester were Age Concern Manchester (voluntary) and Manchester City Council (statutory). A key reason for approaching Manchester City Council was that it had a well-established initiative for improving older people's services – the 'Valuing Older People' programme – that could be built on through this project. Following discussion with local partners, it was decided that the focus would be on hospital discharge. Four co-researchers were recruited through Age Concern Manchester (see Table 13). During the project one of the co-researchers had to withdraw because of caring responsibilities.

Table 13. The Manchester co-researchers

Name	Gender	Age	Experience of service use and caring
Christine	F	60	Full-time carer for her sister
Colin	M	80	Cared for an older relative, and had recent experience of hospital discharge and reablement
Joan	F	65	Had cared for several older relatives and recent experience of hospital discharge
Linda	F	61	Cared for several relatives

6.1.3 Participant characteristics

The original recruitment strategy in Manchester was for information leaflets to be made available to patients discharged from hospital, through voluntary organisations who managed 'Hospital to Home' services. This strategy was only successful in recruiting a small number of participants, and so additional recruitment methods were adopted. For example, the research lead visited a number of community organisations providing services for older people. Carers were recruited through Manchester Carers Forum, who directly approached individuals about the project and passed on a list of those who had expressed an interest to the research lead. In total, 18 people shared their experiences.

All of the 18 participants were interviewed by a co-researcher, with the lead researcher present, with the exception of Catherine, Josie, and Alice who were interviewed together in a focus group arranged by Manchester Carers Forum. Data from the focus group is not attributed to the individuals. The key characteristics of the participants are shown in Table 14 below.

Table 14. Manchester participant characteristics

Name*	Age at first interview	Gender	Ethnicity	Service user or carer
Doris	76	F	White British	Service user
Leonard	91	M	White British	Service user
Terence	85	M	White British	Service user
Brenda	94	F	White British	Service user
Deidre	68	F	Black British	Service user
Gwen	74	F	White British	Service user
Geoffrey	72	M	Black British	Service user
Susan	84	F	White British	Service user
Elsie	86	F	White British	Service user
Catherine	50	F	White British	Carer
Josie	63	F	White British	Carer
Alice	85	F	White British	Carer
Dorothy	79	F	White Other	Carer
Carole	61	F	White British	Carer
Mary	65	F	White British	Carer
Jane	54	F	White British	Carer
Elizabeth	60	F	White British	Carer
Naomi	59	F	White British	Carer

* All names used as pseudonyms

Reasons for going into hospital included heart attack, stroke, emphysema, hip replacement, fall and elective admission. For the many participants, the hospital discharge being discussed was one of several in their recent experience.

6.2 The research findings

The findings of the research are presented under five broad themes:

- Patients, and particularly carers are not always partners in care

- Communication and information issues
- The discharge experience
- Continuity in care
- Home and social support.

The first two of these themes were most strongly related to the early stages of the journey from admission to discharge, while the final two relate to the post-discharge period.

6.2.1 Patients, and particularly carers, are not always partners in care

There was a very strong theme in the interviews that patients, and particularly their carers, did not feel that they were treated as partners in the care process. For example a focus group participant said:

And woe betide you if you question anything because they'll say 'And who are you?' 'Well apart from next of kin or daughter or whatever, I'm actually the carer.' 'Professionally?' they said to me one day. In other words 'Are you on the £7.50 an hour or whatever they get paid?' No, we're on the £53 a week brigade, that's what we get paid! But we're not qualified enough to question. That's how it comes across with medical staff and yet we know more than the people that go actually in through agencies because we've lived with the illness.
(Focus group participant)

This feeling wasn't confined to feeling undervalued (in monetary reward as well as in the attitudes of hospital staff). It also reflected that the expertise the carer had – about service user's character and circumstances, needs and experience of their illness – was not being drawn upon. For example another focus group participant, a carer for her father who had Alzheimer's, explained that hospital staff were unable to take the individual characteristics of service users into account:

He [my father] just come across as such a nasty, nasty, nasty man, but they didn't realise it was his brain damage. My dad can come across really, really nasty and they'll think cantankerous old bugger or whatever, they don't realise he's got dementia or Alzheimer's or Parkinson's, you know, and to deal with that side of it. Unless you wear a label you can't see what's wrong with the person and they just assume. A lot of hospital staff assume, they all, if you've got Alzheimer's you're all in the same pot, but everybody's Alzheimer's is different, everybody's physical disability is different and they did not take it into consideration. (Focus group participant)

However, the lack of partnership in care was not experienced as only one way, with healthcare professionals not inviting patients and carers to be partners in their care. One participant expressed some dissatisfaction at other service users who failed to engage with the service when

opportunities were given. Geoffrey had had a number of hospital admissions relating to his heart condition, and was an enthusiastic supporter of activities run by the hospital:

We've got what's known as a support group, and each time they hold one, you've got the cardiologist and the different professionals, they come and give you a lecture. They send out these leaflets to everyone, and then in a lot of cases people don't turn up. A lot of people just ignore it, and the only way you're going to, anything is going to happen, you've got to be prepared to learn. You've got to be prepared to listen. They are doing what they can, and if you don't cooperate you're not helping yourself, so all in all, the system is very caring, but you have got to play your part as a patient, and I find a lot of colleagues, like myself, they're not responding. I've known people with pacemakers and each time I turn up and these support groups, I never see them. (Geoffrey)

The lack of partnership was also felt as a struggle for services, with an assumption apparently being made about what the carer could achieve, and some confusion among hospital staff about what services were available. For Jane, the caring role was reversed when her mother (also her carer) had a spell in hospital after fracturing her wrist. This required Jane to become carer for her mother, but she experienced unwillingness on the part of some hospital staff to recognise her in this role, which led to confusion at the time of discharge:

One minute they were saying she was coming and she was fit, the next minute they said no she's not fit, then they'd, sort of, say 'Well who's at home', I said 'Well it's me. My sister will help but she doesn't live with us'. I felt sometimes that I'm stood there on the walking frame and if my sister had turned up, they'd be talking to her more. (Jane)

Jane also felt that her limited capacities as a carer were not being fully considered:

It was a bit, sort of, a challenge to get the care because they kept saying 'Well can't you do it' and I said 'Well, I do my best but I can't do everything'...I realised that she couldn't, sort of, dress herself with her wrist being like it was and also I can't really dress her because it takes all my time to dress myself so, and apart from that, I knew she wouldn't be able to cut food up very well because when we went to the hospital, we were cutting her food up sometimes and things like that, so I seemed to have to fight for the tea time [carer's] call but eventually, we did get it. But it was, you know, 'Well why can't you just have meals on wheels and why can't you have your sandwiches at tea time'. (Jane)

It was carers, in particular, who described frustrations about not being a partner in the care of the person they cared for. There was a clear distinction between this aspect, and the communication and information

issues which are described in the next section. A felt lack of partnership was less about information and communication, and far more concerned with issues about respect for knowledge and understanding and recognition of the role that carers played.

6.2.2 Communication and information issues

Participants identified a wide range of communication issues, including being denied information about the service user's condition or elements of care, a lack of information about services and poor communication between services. Carole's husband, who has severe breathing difficulties, had recently been discharged home and was being visited by a nurse from his GP surgery. Neither Carole nor her husband had been informed, in detail, about his condition:

And [the nurse] asked me how I felt about his illness, she actually said to him 'Did anybody at the hospital come to you and tell you the seriousness of your condition?' and he said 'No'. And she said the same to myself, 'Did anybody take you in a room and talk to you?' 'No.'
(Carole)

Another participant described how hospital staff became defensive when discussing a medication error, which severely constrained communication:

They've got that fabulous poster in hospitals now, 'Our staff will not be abused'. Rightly so, but this particular day when we questioned this member of staff 'Why did you overdose my Mum twice' basically and she looked at the poster as if to say I'm threat...you know, you're being abusive to me...And she looked and she said 'I'm not prepared to answer these questions anymore' and she got up and walked out and she said 'Can you leave my office now' and my daughter said 'Well no not really, not till you've answered our questions'. Next thing, security. We'd not raised our voice...I do look at people's faces, now whether that comes across as aggressive because I have to lip-read but she felt attacked, was her words, attacked by my line of questioning. (Focus group participant)

In other cases lack of information had more practical implications, when carers or service users were unsure about what to do once they had left hospital. Mary found it difficult to obtain the information she felt she needed about her mother's condition so that she could understand in more detail how to care for her:

I think if people explained what was happening [it would have been easier] and nobody seemed, at the hospital, nobody seemed to have time for me to say look this is what's the matter with her, this is how she should be treated, nobody had time. (Mary)

Similarly, Deidre was uncertain about what she should do when her ankle started to swell after an operation. She had assumed that her GP would contact her and she also had a follow-up appointment at the hospital:

I came home, hoping that they had done all the communication with the clinic that was arranged to look after me when I came home. I waited, gave it 2 days and I had to ring them back to let them know the nurse hasn't been to see me because I had an appointment to go back, you know, outpatient. And by then I could feel my ankle started to swell up and it was swollen that my son even saw it. I knew I had an appointment on the Wednesday to go back and I thought, I waited, you know, I didn't want to, when I began to get pain and a certain feeling, I wanted to go back, to go in outpatient, but I waited for the appointment that I had to see the outpatient, the doctor, and it was when I went back and they undressed it and it was...all black, it was all black, my toes were black. (Deidre)

Communication difficulties were not only experienced with health care professionals. One carer told how she had significant difficulties obtaining basic information about care homes for her mother:

So trying to get hold of even an address list of care homes in this area, it wasn't quite impossible but it was really, really hard work and I ended up taking the car round the streets and looking for them. (Focus group participant)

Difficulties in communicating about discharge was a common theme with many participants reporting that there was uncertainty about when, and how, they or the person they cared for would be discharged. Brenda, for example, found out her discharge had been delayed only when a nurse came to take her blood pressure, after having experienced a lack of communication from the doctors who were treating her:

Well I saw this doctor and he did come with, I assume his secretary, and it was his registrar, and they just sat at the bottom of the bed. Now, normally, I ask a lot of questions, but I was so, I really thought that I'd get properly looked after and I was ready to listen to anything they said, you know, instead of asking a lot of questions. But he didn't, they didn't talk to me, they talked between themselves and then they said that I could go home the following day and...they changed their mind the following day. I assumed I was still going home, and I'd asked whether they would phone my son...And it was when, during the day, the nurse comes along with the blood pressure, so this lady [fellow patient] said, she won't want that today, she's going home. And she said, 'No, she's not, she's going home tomorrow'. Now nobody had come and told me that until she said that. (Brenda)

3Leonard had a very positive experience of his hospital stay, but he was confused about when he would be discharged.

I've no complaints whatsoever. The doctors were wonderful, the nurses were wonderful. I've got to say that because it's quite true. The only thing was that I was in there exactly a month and after a fortnight they kept saying you'll be going home perhaps tomorrow. And when tomorrow came they said well it'll be weekend. Then when weekend come, they said it'd be next Monday. And I said 'You keep pinching days off me'. (Leonard)

A number of patients' and carers' perceptions of services or facilities were based on information or experience that was dated, or available only second hand, for example in the media where there have been many stories of service failures for older people. For example, one participant explained how she didn't like one hospital she had been a patient in, because of difficulties she had had in being transported home some time ago. Elsie was living on her own, receiving care, but was adamant that she wasn't going into a care home. The conversation with the co-researcher considered the differences between a 'home' and sheltered housing:

I'm not going in Old Folk's Home, no, oh no, no, I'd rather die. I have put in for, got on the list for sheltered housing...You see, I think in a nursing home, Old Folk's Home, people are in bed and they never get out.

Co-researcher: I know that's how you perceive it because I think that's how you...

Interviewee: I'm going back [in time], aren't I?

Co-researcher: You're going back a long, long time, it's not like that now, you know.' (Elsie)

6.2.3 Discharge

This theme considers issues around discharge, distinct from the theme of communication and information considered above. For many participants, the actual process of being discharged was not a significant issue, and hardly featured in conversations. Two participants, however, did highlight issues with the discharge itself.

Doris had been told that she was waiting for an ambulance to take her home, but towards the end of the day, a taxi turned up instead. He hadn't come with a wheelchair, which caused further delay as he had to go off and get one. And when she arrived home:

I came home and, of course, I was just dropped off out on the road, as taxis do and, you know, if you have an ambulance, you expect the men to see you to the door at least, because I've got three flights of stairs to come up and so I was just abandoned there. (Doris)

Mary's mother, who has dementia, was taken home in an ambulance. Mary waited at home for the ambulance to arrive:

Well for a start, she had, at the hospital she had dressing gowns, bed jackets, her slippers, bed socks and she was in that ambulance in the middle of winter, in a short sleeved cotton nightie with a cotton blanket round her and that's how they sent her out. Nothing on her feet, everything was in this big green bag, or grey bag, and the ambulance driver said to me 'Oh we've had an awful job', so I said 'Why?' He said 'Has she broken her hip?', so I said 'No, why?' He said 'Every time we've turned a corner, she screamed and we thought she was hurting somewhere', I said 'No, my Mum's got dementia, she wouldn't know where she was, where she was going' and with her lying down and, of course, things moving, it wasn't what she was used to, she didn't know what was happening and every time they went round a corner she screamed her head off and these poor ambulance men thought she'd broken her hip. (Mary)

Moreover, the ambulance staff did not know that Mary's mother was bed-bound and had to be taken upstairs. They didn't have the appropriate equipment to take her up the stairs, and so ended up struggling up the stairs, which Mary described as a 'dreadful experience'.

6.2.4 Continuity and responsiveness

A number of interviewees reported that services at home often lacked continuity and/or responsiveness. The main issues were multiple assessments, different carers and services being unable to be flexible according to needs, including those that varied from day to day. Having a number of assessments was mentioned by several participants; this wasn't necessarily a significant negative experience, rather more frustrating and irritating. Carole talked about needing assessments from both social services and health services:

It seems like one after another coming in for doing different assessments on something else every time you know...It's not one person comes in and assesses for everything, it was like a never ending stream of people coming. (Carole)

These assessments included financial assessments, which came after assessments for care, which meant that decisions were difficult to make because of uncertainty about the financial costs of care to the family.

The theme of different carers being allocated was mentioned by several participants. Elizabeth cares for her mother who is bed-bound and has Alzheimer's. On one occasion, she was informed that a new carer – who needed to make up their hours – would be covering the regular respite cover shift. It transpired that the sit-in was down for the wrong time on the new carer's rota, despite this being agreed with the care agency in advance. Elizabeth's account of the subsequent telephone call illustrates the importance of the relationship between carers and clients, and the need on this occasion to be assertive to get the service required.

Back on the phone!...I said [to the supervisor] 'How come?' and she said 'Well [the new carer] needs to make up her hours', and I said 'Well that's not my fault, that's your business'. So she said 'Well, it's easier to make it up on the two sittings' and I said 'What about the other two girls? They're losing two hours each. They need the money just as much as anybody else and besides one of the times doesn't suit'. She said 'It's the only time [new carer] can do it' so I said 'Well it doesn't suit me, you better change it. I want [my usual carers] back'. So [the new carer] was upset with me...She was told...that I'd phoned in and said I didn't want her. I didn't want her mainly because of the time on Thursday and Mum is used to the usual carers...and I'm not changing that. So she was more or less telling me that I couldn't interfere, so in the end I got onto my social worker and said 'Will you tell her?' and it was changed. (Elizabeth)

Several interviewees highlighted that their needs changed from day to day, and that the care they received wasn't able to respond flexibly. For example Susan, who lived alone, had recently had a hip replacement as well as having other health issues. She said that:

Sometimes I feel that I can't even go and make a cup of tea. Another time I can go all day without anything to eat. I mean I've had nothing today, not had any breakfast...But I don't know whether I should have anybody in to, it's only when I feel that I can't do anything. I mean other times I make myself go in, because like I say you do seize up. If I don't keep moving, I won't want to move at all and me bones won't work then and I'm frightened of seizing up. (Susan)

One focus group participant who cares for her sister told how the care staff who helped her to bed came too early, and it wasn't possible to put the visits back:

The evening staff, they'd come at half past six to put her to bed, well that's far too early, so she used to let them put her into bed and then get up and after that I had to put her to bed...And I said to the social worker, I said 'Really, we don't want, we'd be better off without the evening staff because I have to do it anyway', and I couldn't get them to come about eight o'clock and, I suppose they have to go and see everybody, they can't be at every house at eight, but half past six in the evening is too early for a night. (Focus group participant)

Direct payments weren't a feature of users' or carers' accounts, which is perhaps unfortunate as this is a central policy in improving the responsiveness of services. Only one participant, Doris, had experience of direct payments, and this was unfortunately a negative experience, where she felt unsupported in a process that seemed more about administration than ensuring she had influence of the caring services she received:

This man, my broker, got about 32 replies, what has he done? He's given them all to me and I've had to spend a whole evening going

through every one of 32 letters and CVs, you know, I feel as if I'm working without pay. And he's also given me, I thought someone was organising this for me, he's given me a list of about 32 telephone numbers to phone all these agencies, you know, me to do it. Why doesn't he do it or someone else do it. (Doris)

6.2.5 Home and social support

Social support was seen as crucial in managing at home after hospital discharge. For example, Mary talked about how valuable the support was that received from a friend – a neighbour – in her caring role.

My friend comes every day apart from Wednesday, because sometimes I've got washing three times a day and what have you, and she just walks straight through the door, looks through the back window and sees what's on the washing line, she brings it in and irons it for me, so she's a wonderful friend...She does most of my shopping for me and she'll take me out shopping and she'll say 'Oh you sit there, I'll go and give your Mum a drink. (Mary)

Leonard lives alone, but has regular support from his family:

Oh I'm well looked after by family. I have a daughter in law...She comes and takes me there for a couple of nights, quite often, and my other step sons come...and take me to lunches and dinners. [I am] well looked after and well cared for. (Leonard)

When asked about a single message she would give to people providing hospital services, Gwen talked about paying greater attention to the support needs of people living alone. She recounted the following experience:

Be especially careful with people who live on their own. I made a friend, well she made friends with me. A lady 81 that was in the bed next to me, who cried when I was coming home because she didn't want me to come home and she lived on her own and she was worrying about what would happen to her. (Gwen)

The absence of social support was significantly felt by Elsie, who had been first in hospital and then a rehabilitation unit for three months. She lived on her own and although her discharge was well managed, when she was left in her flat after the discharge, was 'Very lonely and I felt cut off':

And then the time came when they said I was ready for home, this has now gone into three months away from home. But I really didn't want to come back here, because this last four years, a hell of a lot has happened to me, I've never gone a year without something going wrong. I've been in and out, visiting hospitals since 2007. Anyway, they fixed me up with the oxygen and I, well, I still didn't want to come, but I had to go somewhere. And then two nurses came and the man with the oxygen, he had to measure this lead and everything,

then I was left on my own. Well, I just couldn't believe it, it was a horrible feeling. (Elsie)

Elsie described how some local businesses – a taxi firm and a local shop – had known her for a long time, and provided additional support by, for example, transporting her oxygen cylinder, delivering groceries and helping to put them away.

Several interviewees mentioned that having someone to 'fall back on' was highly valued. Sometimes this was a supportive family member, but others mentioned a health professional, in Dorothy's case a social worker:

She says I can ring her any day and we have a nurse who comes in twice a week to look after him and we have a very, very nice doctor, a lady doctor, she ring us, like today, and she say 'Tomorrow I'm coming, half past seven coming and look after him'...If we needing anything, she will come. The pharmacy people...they're willing to help with anything, if I need medicine, I ring him and he passes a message to the doctor and I have the medicine here in an hour. So really, really, we are really looked after very well. (Dorothy)

6.2.6 Suggestions for improving services

There were a number of specific suggestions made about how services could be improved: for example better hospital food, making carers available more flexibly, having a single assessment and improving ambulance response times. The two major themes in these concluding comments were for staff to listen to services users and carers, and for staff to be more 'caring' in their approach. The first point was particularly highlighted by carers, and reflects the themes identified above about partnership in care and information and communication. For many participants, and particularly for carers, hospital discharge was not a one-off transition, but rather a specific event in a series of transitions related to their condition, or other aspects of their health. In this context, the need for good information and communication was therefore ongoing. Comments about being staff being more 'caring' related in the main to issues of respect, attitudes and communication.

6.3 *The implementation phase*

6.3.1 Feedback and Transition into implementation

There was difficulty creating a formal local advisory group that could meet regularly to support this research. However, there were two key people from Age Concern who were very supportive during the research phase, interest and support from a key individual in Manchester City Council (MCC), and three very enthusiastic co-researchers. These six people worked

together with the research lead to plan local dissemination of findings, as a first step toward local change.

As senior statutory representatives had expressed a preference to wait until phase one findings were available, a first meeting was arranged near to the dissemination event, to explain the project and discuss emergent themes and our desire to support local sites to implement the findings from this work. Unfortunately attendance at this meeting was limited to one colleague from the NHS and two senior colleagues from the City Council. A key issue discussed at the meeting was the distinction between research which offered evaluation of specific services, and research which concentrated on developing an in-depth understanding of the experiences of people using services. Other themes discussed included the 'representativeness' of the experiences presented, and the traditional preference in service evaluation for quantitative measures.

This meeting, and indeed the dissemination event itself, took place at the end of March 2011, when MCC staff were deeply concerned with setting budgets for the following financial year because of significant reductions in public spending; MCC had been in the news very recently about the number of redundancies that would be planned. At the time of the meeting at the City Council, several colleagues invited sent their apologies, as urgent budget considerations took priority. This was followed by a second planning meeting with Age Concern, who were hosting the event.

6.3.2 Negotiating the interventions

The feedback meeting, held at the end of March 2011, was attended by 27 people, around one third of whom were from statutory health, social care and housing services and the remainder made up of voluntary organisations, carer and older people's groups. In the morning, the co-researchers together with the research lead fed back the research findings. This comprised a presentation and significant extracts of participants' stories being read out by co-researchers, which brought the findings to life. The impact of this design felt profound, as those present began to connect with the issues and spoke to their own experiences of services. The stories also brought some dismay and scepticism: 'Many of these issues are so familiar, and have been around for years...why is it that these issues are still current?'

This was followed by work in four small groups. Membership was distributed to ensure a reasonable representation across NHS, Local Authority and third sector colleagues, and each group included a co-researcher or researcher. Groups were asked to identify improvements that could be implemented at individual, service and strategic levels, and to prioritise actions which would have the greatest impact on service users' experience of services. A total of 28 different actions were identified, so a further exercise to prioritise these was undertaken (see Table 15)

Table 15. Priorities identified in Manchester

Individual Level	Votes
On admission: Improve process of information gathering; need to have information to care and for discharge planning	9
Service Level	
Use people who have been service users to train staff	9
Better provision of information to support patients	7
Communication: introducing to patient/family, key workers, life stories/passports	5
Strategic Level	
Move away from process led decision making to person centred decision making	7
Redefine the Manchester Patients Care offer and the role that all parties play in supporting transitions (NHS Staff/Local Authority/third sector/natural carers)	5

The event concluded with a presentation from the Programme Manager (Integrated Community Provision) for MCC to illustrate developments and progress with integrated care in Manchester. This was an important addition to the event, because any follow-on implementation from this research needed to dovetail with existing developments and change, so that it could be embedded in services. This approach also fitted well with the context of cuts in local authority budgets and the need to find significant 'efficiency savings' in healthcare, rather than developing new initiatives.

6.3.3 Taking actions

The process for taking actions had not been decided at the end of the event, and there remained a question as to what next and how? We were aware that this transition – from research into action – needed to be managed well otherwise there was a danger that our process would mirror many service transitions: things fall through the gaps!

MCC made contact soon after, keen to take forward actions from the feedback event, and link this in with work that was already underway. The two priorities that they wished to take forward were:

- Move away from process led decision making to person centred decision making (in assessments)

- Involve/use people who have been service users in service evaluations.

They had piloted a single assessment process to bring together assessments for equipment, reablement and long term social care needs, and reduce the number of assessment contacts from around nine to one or two. The six month pilot in the south of the city had proved successful, and an evaluation showed that 97% of customers¹ felt the service had been excellent. In addition, the number of people moving into reablement – one of the aims of their changes – increased by 50%. Previously around 50% would require longer term interventions, and this had dropped to 25-30%. The main reason for this improvement was that customers were accessing services more quickly as a result of the single assessment process.

MCC now planned to roll out the single assessment process. However, before doing so, they wished to refine the assessment process itself to focus on the strengths as well as the needs of customers, and place 'ability' rather than disability as a central concept. This meant changing both the tool used and the philosophy of practice that governed the mindset and behaviours of practitioners.

In addition, MCC wished to build on, and embed, an on-going relationship with service users and carers. The transitions project offered a real opportunity for this through the development of a group of co-researchers who could become a local resource; in this case to follow-up the survey results with more in-depth interviews with services users, and work alongside staff to analyse the data and present findings.

As each site was awarded consultancy support by an OD lead, it was decided to use this resource for the two parallel activities:

- Intelligence gathering on single assessment tools to identify those which focused on ability rather than disability and were governed by a process that is co-produced. This would include identifying services across England who are leaders in this field and inviting them to contribute to a workshop for local staff.
- An in-depth qualitative evaluation of older people's experiences of the single assessment process and identification of areas for improvement. This would be led by the co-researcher team and supported by an individual identified and trained to act in a coordinating and supporting role. The co-researchers would carry out interviews and, supported by the coordinator and MCC, analyse the data, write this up in a report and present the findings to local service providers and agencies.

A number of complexities were experienced along the way. We found very few examples of services for older people undertaking holistic, person-

¹ Term used by Manchester City Council to describe the people who use their services

centred assessments, and those that were doing this work were fatigued from reorganisations and redundancies, so were unable to attend the planned workshop. This led us to look to examples of good practice from direct payments and personalisation which had been around for more than a decade, and explore how the learning from this area could inform the work.

For the follow-up of customer experiences, someone who had recently taken voluntary severance from social services was identified as a good candidate for the coordinator role, but because they had recently been made redundant, was not able to be paid by the local authority. Furthermore, MCC did not have a policy for paying service users and were not able to pay travel as their HR rules stated that they could not pay 'employees' travel to and from their place of work. The project had allocated funds for implementation and dissemination, and a small amount of this resource was used for payment of the coordinator's time and co-researchers' travel expenses. Other practicalities were also supported, such as administering CRB checks.

In September 2011, the workshop was held, with 25 health and social care staff from across different services attending. Staff were well engaged and active, but the impact of cuts and reorganisations were taking their toll, and there was a degree of 'helplessness' spoken to, which at times got in the way of the work. Nevertheless, staff commitment prevailed, and a series of tangible actions emerged from the day, focusing on the integration of assessment processes across health and social care rather than holistic assessment. Tasks identified included joint inductions, assessments and training, shared data and IT systems that could be accessed by both health and social care, and shared briefing/development sessions. These were allocated against named staff to take away and progressed.

While the focus of what emerged was disappointing from a perspective of enhancing person-centred practice, it was positive inasmuch as it addressed other priorities identified at the feedback event, such as better communication and integration between services.

For the second strand of work, an initial meeting to bring together representatives from the new Primary Assessment Teams (PAT), the co-researchers and the co-ordinator took place in July. Following the approach of the Transitions project, a 'spine' for the narrative interviews was developed, information and consent forms were developed, participants were contacted for interviews and timetables planned. Eight recent PAT customers in Wythenshawe were visited in their home and interviewed about their recent experiences of their transition into social care.

Two workshops were arranged to prepare for and then undertake the analysis. The first, in early January 2012, was a meeting with co-researchers to hear about their experience and look through the transcripts to see what themes were emerging. From this a number of thematic categories were suggested which reflected both the work of the PAT service

and also picked up on some categories in the EQ-5D health-related quality of life questionnaire which MCC used to assess some of their services. Categories were refined and put into an analytical framework which was then sent to the co-researchers and PAT staff who would be involved in the analysis.

At the end of January 2012, a second workshop was held with members of the current Wythenshawe PAT together with the District Manager to analyse the interview transcripts. In the workshop, the words used and stories that interviewees told were discussed, the key themes were analysed and learning/action points examined. Notes from the workshop were taken and a set of themes and issues developed against the two objectives: 1) Evaluating the new Primary Assessment Service and 2) Determining the value of a user-led narrative approach to enhance service evaluations. On the 28th February a report was presented to senior managers at MCC's Adults Health and Well-Being Directorate meeting, in which the following themes, observations and actions were highlighted:

Evaluation of the new Primary Assessment Service

In exploring the customer stories some key themes were identified by the workshop attendees:

- Organisational structures are not recognised or understood by customers, and issues are not compartmentalised as Housing, Health or Social Care.
- Customer anxieties are wide ranging – including money, loneliness, lack of appropriate information, support and less ability to do things/dependency on others.
- The Primary Assessment Service itself was well liked, including the Reablement Service and the timely provision of equipment. Some customers described the transition from reablement to either home care services or where no long term statutory services were put in place as rather 'abrupt.'
- Anxiety and personal concerns about ability to manage and cope after services ended were prominent in the customer stories. Those with strong family ties and stronger local networks appeared less dependent and expressed more confidence about their situation.

Key learning and action points

- Improving the handover from PAT/Reablement to Home Care once the 6 week service finishes to better support the transition for the customer.
- As part of assessment and support planning, look at creating a 'support tree' with the customer to identify their local support network and ensure reablement is focused as much on being out and about with the customer, as re-establishing home based skills.

- The importance of the availability of social care staff and their local knowledge of universal services to tackle social isolation.

Reviewing the experience of using customer stories and co-production

After the workshop with staff, they were asked to feedback on the value of the customer stories and the approach to analysing the interviews. All felt that reading, discussing and analysing customer stories was helpful in a number of ways, with different team members voicing different points which led to good discussion:

- Although the customer stories could not be regarded as new it was felt that this was a way of keeping service redesigns and service improvement centred round users and carers.
- Hearing the confusion expressed by customers about MCC provided a clear reminder about how complex health, social care and housing are to navigate.
- The sample size (n=8) was small and therefore some caution must be applied as to the significance of the evidence for service improvements.
- Customer stories should be considered as just one of the elements and approaches to performance improvement.

Recommendations

- MCC proposed that patient/customer engagement functions in health and social care organisations look to embed a user and carer led approach to evaluations as part of a shared strategy of involvement in service redesign and service improvement.
- Due to the resource needs and effort involved in preparation, execution and analysis of the customer stories it is recommended that the engagement exercise is carried out on a locality basis (North, Central and South), jointly owned by health and social care, twice a year.
- The proposals could be extended further into all customer groups (learning disabilities, mental health, physical disabilities and partnership boards).
- The specific details of who is to be interviewed (what cohort of patients/customers) and support arrangements for volunteer interviewers should be made on a locality basis and agreed by local health and social care managers, in partnership with customer/patient engagement leads.
- The resource needs (and potential costs) for creating the written transcripts from recorded interviews needs to be considered as during the pilot study each interview took 3 to 4 days to prepare as a

transcript. Alternative approaches include filming the interviews - this would require appropriate media editing facilities and resources.

Actions

- MCC Programme Manager (Integrated Community Provision) and OD lead to design an infrastructure and training programme for co-researchers.
- The customer engagement manager will work with patient engagement leads across the three acute hospital trusts to identify funding, resources and an engagement plan for a 12 month trial by 31/03/12. During the co-researcher evaluation of the PAT service, local hospitals heard of this work. While all three acute health trusts in Manchester had experience of using a patient stories approach to gain insight about services, these have typically been conducted by staff members rather than an independent peer-to-peer approach. Through preliminary discussions with senior colleagues at all three hospitals, all are interested in using the user/carer researcher model as part of a joint customer/patient engagement strategy as MCC implement the integrated care model. Medical consultants and GPs are particularly keen on customer stories to inform learning.
- Plans to be presented and agreed at three Clinical Commissioning Groups.
- Run a city-wide trial for 12 months and review at the end of the 2012/13 financial year.

Manchester City Council's Adults Health and Well-Being Directorate approved the actions and work is now underway to realise these plans.

7 Older people living in rural areas (Gloucestershire)

7.1 *Background and context*

7.1.1 The local area

Gloucestershire is situated on the northern edge of south west England and has a population of approximately 589,100 people. It is described as a rural county although most of the population live in urban areas in the cities of Gloucester, Cheltenham and Tewkesbury or the rural towns of Stroud and Cirencester. However, the proportion of people aged 65 and over in the county is higher than the national average (17.7% compared with 16.1% nationally). A larger proportion of older people live in rural areas, such as the Cotswold and Forest of Dean districts. The 2001 census results showed that one in eight of all rural households in Gloucestershire do not own a vehicle. Moreover, a large proportion of the over 75 age group in the county live alone (48.2%).

7.1.2 The study in Gloucestershire

The LPAs in Gloucestershire were Gloucester Older Persons' Association (GOPA) and Age UK Gloucestershire (voluntary) and NHS Gloucestershire (statutory). Age UK were unable to take part in the project initially due to a local reorganisation; they became a partners at the beginning of 2011. The decision to focus on hospital discharge was not only made because this was an area of concern shared by the LPAs. Additionally, Gloucestershire Local Involvement Network (LINK) had started a Hospital Discharge Pathway Task Group and it was felt that the research findings could add to this work. Three co-researchers joined the project, who were recruited through GOPA's networks (see Table 12 for details). Sadly Peter died shortly after the local meeting to feed back the findings from the interviews.

Table 16. The Gloucestershire co-researchers

Name	Gender	Age	Experience of service use and caring
Peter	M	76	Experience of hospital a number of times over the previous two years for liver care
Pauline	F	66	Been in hospital the previous year following a heart attack
Roger	M	59	Acted as a carer for his mother and father

7.1.3 Participant characteristics

The recruitment of interviewees began by circulating information about the project through GOPA and the Village Agent Network run by Gloucestershire County Council and Gloucestershire Rural Community Council, but uptake was very slow. The majority of interviewees were recruited through Age UK. Potential participants were identified from their database of people using a hospital aftercare scheme and contact by a member of staff. If they agreed their telephone number was passed to the research lead who rang and provided further information about the project. The initial slow recruitment made it only feasible to interview participants once. The main participant characteristics are shown in Table 13. A number of older people attending the feedback event talked about wanting to be addressed formally as 'Mrs X' or 'Mr Y' by services, until a closer relationship had developed. With this in mind, the pseudonyms used below are formal, rather than by first name.

Table 17. Gloucestershire participant characteristics

Name	Age at first interview	Gender	Housing situation	Service user or carer
Mrs A	78	F	Living with spouse	Service user
Mr A	80	M	Living with spouse	Carer (of Mrs A)
Mr B	78	M	Living with spouse	Service user
Mrs B	77	F	Living with spouse	Carer (of Mr B)
Mrs C	70	F	Living with spouse	Service user
Mrs D	91	F	Living alone	Service user
Mrs E	80	F	Living alone in warden controlled	Service user
Mrs F	70	F	Living with spouse	Service user
Mrs G	79	F	Living with spouse	Service user
Mrs H	84	F	Living alone in warden controlled	Service user
Mrs I	84	F	Living alone in warden controlled	Service user
Mrs J	65	F	Living alone	Service user
Mrs K	85	F	Living alone	Service user
Mr L	81	M	Living alone	Service user
Mrs M	65	F	Living with spouse	Service user
Mrs N	84	F	Living alone	Service user
Mr O	84	M	Living alone	Service user
Mrs P	85	F	Living alone	Service user
Mrs Q	79	F	Living with spouse	Carer
Mrs R	57	F	Living with spouse	Carer
Mrs S	25	F	Living with spouse	Carer
Mr T	55	M	Living alone	Carer

7.2 The research findings

The findings are presented as they were at the local feedback event, under the four main headings of the patient journey: firstly, going into hospital, where fear of hospital, the possibility of a loss of independence and uncertainty about what would happen next are the main themes; secondly, being in hospital, where issues relating to lack of involvement in decisions and the attitudes of staff are raised; thirdly, being discharged and the distress caused when this was prevented; and finally, life back at home where the major themes were the importance of effective discharge planning, the huge responsibilities placed on carers and their concerns about the way their views are not taken into consideration.

Most of the participants were living with a chronic condition before their recent stay in hospital and just over half of the participants (n=13), including four carers, had multiple conditions. Nine had been in relatively good health before they were taken ill on this occasion, but for many of the others there had been a gradual deterioration. The majority of those interviewed entered hospital by ambulance and arrived through the accident and emergency (A&E) department.

7.2.1 Going into hospital

Fear and uncertainty

It was clear from their explanations that most of those interviewed were afraid of hospitals and associated them with a loss of independence or even death; although they were grateful for the care they received. A typical example was Mrs D, a 91 year old woman who was taken into hospital as an emergency with diarrhoea and sickness:

I'd dreaded going to the hospital, particularly [name of] hospital, because I do think you bring out more than what you take in, but I was feeling so ill I didn't mind. (Mrs D)

Four of the respondents had a planned admission to hospital and in these cases the journey, the parking and finding the right department were the main factors that concerned them. These were of particular concern where the hospital was unfamiliar.

Travelling to and from hospital was also a major cost for those living in rural areas. For example Mr A commented:

So that's the only thing, the petrol consumption, but I get used to driving to different hospitals and looking at the petrol pumps to see which is cheapest. (Mr A)

For two of the respondents who had a booked admission, waiting for the appointment was also a problem. In one of these cases, Mrs F, a 70 year old woman who had a back problem, she had been put on the wrong list (for a spinal route block instead of a decompression operation), which

delayed the operation. In the second case, Mrs G had been re-assured by her GP that, as there was a wait of fourteen weeks for the hip operation, she and her husband could go on holiday while they waited. When they returned they were horrified to find that Mrs G had been put to the bottom of the list and now had a wait of 20 weeks. Mr G 'Rang up everybody I knew' and Mrs G was admitted for her operation within a fortnight of his complaints.

7.2.2 Time in hospital

Lack of involvement in decisions

Once in hospital many participants' fears about losing independence were realised because their experience was one of lack of involvement in decisions. Things happened to them without explanation. Mrs N, for example, who had an intestinal abscess and went into hospital to have it removed and a stoma and colostomy bag put in place, said:

They put me on this ward, which was a geriatric ward and nobody explained anything. They fed me...and they brought me this liquid to drink but they didn't tell me what it was and I didn't realise that it was to go through like that and they didn't bring me a commode and nobody came anywhere near me...luckily the bathroom wasn't too far away, but in the end I had to find a cleaning cupboard to clean myself up as best I could. (Mrs N)

Others had a similar experience:

I was taken up to a ward, but nobody told me what was going on, what was happening and why I was there. I kept asking questions, but I got fobbed off with 'Oh I'll get the sisters to come and talk to you or mention it to the houseman when she comes round'. Which I did and again got fobbed off...things were plonked on my locker with a 'take these', I'd no idea what they were. (Mrs J)

And there were staff going to and fro and I just felt that I was invisible. I was just left there sitting in, I think I was sitting in a wheelchair actually. (Mrs E)

Sometimes differences in wards were identified, implying that care could vary. The admission ward was mentioned by one or two people as being exceptionally busy, leading to inconsiderate care. Mrs E for instance described a particularly unpleasant experience:

And what was very distressing to me was I have for about 6 or 7 years now to self catheterise because my bladder muscles don't work. And you know the nurses on the admissions ward they wouldn't let me out of bed and they couldn't cope with it. They tried to catheterise me lying down, that didn't work. They didn't know how to do it on that ward. There were two of them struggling and in the end they made me sore. All they had to do was let me go to the toilet. It was so

humiliating I nearly died. That was the worst part of admission. Anyway I was only there one day thank god, and in the orthopaedic ward, which I was sent to, the nurses knew exactly what to do. (Mrs E)

Previous experiences of being in hospital sometimes helped participants to identify choices and regain a small amount of control. Mr B for example, mentioned:

I felt a bit, I don't know, I wasn't used to being kind of incapacitated like that, because they wouldn't let me put my leg, my left leg on the floor and of course when I had to go to the toilet, they had to get a wheelchair. But I did ask for a urine bottle, because that was something I knew you could get from a previous stay in hospital. (Mr B)

But often those interviewed felt 'done to' without being offered choices. Mr B, who was in hospital a week to remove a tumour on his leg, would have liked more opportunities to wash, but did not feel this was discussed. He commented:

The other thing is washing, I think they gave me a bed bath once, you know, just brought the basin and flannel and did a bit of me. I'm not used to it, I'm a bath person. I don't think there were facilities on the ward. (Mr B)

This can be contrasted with the experience of Mrs M who was also in hospital for a week following a stroke:

They kept me in a week...I wasn't allowed to have a shower on my own. I had a walk-in shower which was lovely so I had to ring or pull a thing for the nurse. She had to come in with me. They were absolutely brilliant. (Mrs M)

Activities that made older people feel human or taken care of, such as personal hygiene or meals which suited them, were important in the impersonal atmosphere of the hospital. Mrs E for example complained:

I'm vegan and they didn't twig that until the day I was going out. So I was having unsuitable food. I did tell them when I went in, but they didn't get round to sorting that out. That was a bit upsetting. (Mrs E)

This can be contrasted with Mrs D's experience in a rehabilitation unit at a nursing home where she described the food as 'wonderful', adding:

Because when you're ill, you don't eat so much, you want small portions presented nicely to sort of tempt you. You don't want it just plonked on a plate in front of you with a huge great helping do you? (Mrs D)

Attitudes of staff

Small acts of consideration, such as being told what was happening, being asked if you were feeling OK, or being given an apology often seemed to

make a big difference in relieving anxiety or making a person feel better. Mrs A, for example said:

I didn't have a lot of time to think about it because they were waiting for a bed and each time I asked they said 'Yes, there is a bed for you but we're just waiting for a patient to go away' so by the time I got up to my ward I had about 5 minutes to get undressed and into my gown, so I really didn't have any time to think about it and I wasn't worried at all. I just wanted to get it done and that was that, you know I was just very positive about everything. (Mrs A)

Then later, after Mrs A had her operation, she found the nurse on duty flexible over the ward routine and that made a good impression:

I must have gone to sleep and woken up and it was all quiet and the nurse – you know how they do their rounds – came round, and to me it was sort of six o'clock in the morning and so I said 'Is it alright if I go down to the bathroom and have a wash?' And she looked at me a bit, then said 'Yes if you want to', but it was only 2 o'clock. So that was fine. No it was very good, I have no complaints about anything. (Mrs A)

Mrs D was pleased when the GP who had visited her at home before she was admitted came to see her in hospital. Mrs D commented, 'She said I must apologise, she said I didn't think you were so ill, which was nice of her.'

However, many said they found acts of consideration and respect to be few and far between:

But some of them are very rough, they don't, I mean when I had surgery like, you know and they didn't turn you over gently, they grabbed you and turned you over without having much thought that you can't get over and you grimaced and they said 'It's alright, it's all over now'. But if they'd done it more gently you could have helped yourself a bit more, like, you know, but no I don't recommend the hospital. (Mrs N)

This one nurse was bloomin' trying to shove the tablets down my throat. I said hang on a minute, I want to check them, because they didn't have a clue about my Parkinson's tablets and in the end I said give them to me, I'm used to doing them myself. The male nurse was lovely, he'd say 'Oh here you are, only too glad to give them to you'. But the other nurses were sort of, no we dish them out and this one nurse she was sort of shoving them in my mouth literally. (Mrs F)

In most cases those interviewed were keen not to cause trouble or be seen as 'trouble makers' so they did what they were told and accepted their temporary loss of independence until they could return home. This position was exemplified by Mr O who said:

The ward lady said 'It's been a pleasure to have you' and to me it makes me feel happy to think that I had not upset anybody at all, because that's my general wellbeing. (Mr O)

But some seemed to struggle to come to terms with what they saw as unfriendly behaviour from nurses. Mrs N commented:

The thing I noticed more, whether it was health and safety or not, but if you didn't ask you didn't get and I had a walker and my wash bag and my towel plus my colostomy bag, which I had to struggle to take to the bathroom and a nurse would pass you and not even ask you if you wanted any help and I mentioned it to another nurse that I was struggling, who was a nice person, and she said 'Well you mustn't do it, you must ask, if you don't ask they won't help you'. (Mrs N)

She added:

It was all so clinical and I think because I'm old, I remember the days when I was younger in hospital, they seem to lose that one-to-one with the patient. You didn't have the understanding that you did from the nurses that were in the old days...I said to my son, I've had three lots of hospitals now and I don't want to die in hospital because the experience I had is cold, it's not as it used to be. (Mrs N)

Mrs N's comment about wanting to be asked whether she needed help rather than having to ask for it herself was fairly common amongst those interviewed. Others found it difficult to identify different types of staff or to know what their jobs were:

You couldn't tell the doctors because they weren't very, sort of, they did their job but they didn't look like doctors, you know, as they used to with their coats...there was so many people running around with bits of paper in their hands and I thought well these women don't look very professional. They were running round in long skirts with lots of jewellery round their neck and all. (Mrs D)

Nearly everyone interviewed commented on how busy the nurses seemed to be, which meant they were either not on the wards or they did not seem to have much time to spend with each patient.

7.2.3 Hospital discharge

With one or two exceptions, those interviewed thought they were discharged at the right time. Only one person thought she was not ready and would have liked to stay a few days longer. Two respondents had very distressing experiences where they wanted to go home but were prevented from doing so.

Getting stuck in the system

Mr L spent a week in hospital as a result of collapsing with a stroke and was then transferred to a rural town hospital. But within a few days he became

ill, shivering and in a cold sweat, so they transferred him back to the first hospital where he remained for about three months. During that time he was moved five times into different wards and his experience became very unpleasant. He commented that 'Towards the finish I got that fed up because it ceased to be a hospital anymore', instead it seemed more like a prison. He explained:

I used to try and help myself like up and down the stairs, I used to get the help with the two nurses, we sort of went down, to learn to go up and down the stairs, like this here. I can't use them anyway, I'm better in my own home now, but besides that I used to go out weekends when the physio wasn't about – her weekend off – I used to go a walk, find my way to the stairs and walk up and down a few steps of the stairs. But they used to come after me (Mr L)

Mr L had no one to visit him in hospital and he complained that he had no clothes and the ones he was wearing 'stank' and eventually they helped him organise someone to do his washing on a paid basis. He tried to leave twice but they brought him back. They told him he couldn't manage the stairs to his flat at home because he lived alone on the second floor.

Finally he discharged himself and a taxi took him home without any equipment. The hospital contacted Age UK Gloucester which runs a discharge support scheme and a volunteer called the following day and organised walking sticks and a zimmer frame. He also had a follow up visit from the hospital, and now he has help with his shopping and other issues such as his medication. He prefers being at home despite the difficulties he faces, and appreciates the help he is now getting. He said:

No I wouldn't go back into hospital again, no matter what happened I would never go back into hospital again...Because it's not what it used to be, they haven't got time for anything, they are busy which you can't blame them, because they're not given time to do anything properly. (Mr L)

Mrs K also had a stroke and an ambulance took her to accident and emergency. From there she was transferred to her local town hospital and then discharged home. Unfortunately she fell and was taken back to the town hospital and from there was transferred to a nursing home where she spent eight months feeling trapped. She explained:

In that nursing home I sat in a chair and I went to bed, I had my room, I had my own bathroom, everything was very nice but I, oh my god, I was just sitting there. Do you know I got stiffer and stiffer. I needed movement. I didn't get any. (Mrs K)

She felt as if she would never get home and was very depressed but eventually one of the nurses helped her.

I said, 'I've got to talk to somebody' and one of the nurses said to me, 'Have you seen a social worker yet?' I said 'No' and that was the point

things started to happen. They were very good I've got to say, and they said 'We'll get you home'. (Mrs K)

Shortly afterwards she was discharged home with a support package including physiotherapy.

These unhappy experiences can be contrasted with those of Mrs D who was also moved about from one location to another but felt she was on her way home rather than being moved around but not going anywhere. She was moved to a cottage hospital where she had physiotherapy every day. Then she was moved to the rehabilitation unit at a local nursing home where she practiced routine daily activities.

For most people the discharge was a welcome event but many mentioned that it was taken for granted that a relative or friend would collect them. There was also frequently a lack of information. In one or two cases this concerned the medication they were given, but more often it related to arrangements following discharge, support groups or agencies providing support services such as Age UK.

7.2.4 Life back home

Half of those interviewed or being cared for lived on their own and several of these returned to an empty house when they were discharged from hospital. Given the prevalence of multiple and serious health conditions among these older people, it was not surprising to find that they struggled to look after themselves when they returned. A number mentioned feeling weak and experiencing a shock at the contrast of returning home after being in hospital. Some spoke of feeling abandoned. For example, Mrs E commented:

But they didn't make sure that there would be somebody here when I came home. My daughter who lives near had an infection so she couldn't come anywhere near me. And I came back to an empty flat and after being, you know, looked after hand and foot, and had to set to and do everything for myself, which was not very pleasant. (Mrs E)

Those who lived in warden controlled accommodation or with their spouses were in a better position because there was someone to make sure aftercare services started. In a number of cases aftercare started as planned and this was appreciated, as Mrs H recalls:

So after two weeks they told me I could go home but I had to have oxygen in the house so this was all arranged for me the day before I came and then I came out and since then I've had really good help. I've had morning, midday and five o' clock. Someone's come in each day, just to see if I could manage on my own, and the help's been wonderful. I can't fault it honestly. (Mrs H)

Poor discharge planning

A typical experience that participants shared was chasing up services following the patient's discharge. For example:

I got nothing on discharge. I think they told me that the district nurse would be coming to see me. I was discharged on the Friday and I think she was supposed to come on the Monday, but she forgot and I had to ring up and say is anyone coming? (Mr B)

I had to get the district nurse. There was a letter, but I had to ring them up and arrange it. They hadn't rung my GP. (Mrs F)

One nurse at the hospital she gave me a Red Cross contact which I tried to phone and couldn't get through and so eventually I phoned social services in Gloucester who put me in touch with Age UK. (Mrs I)

There was some indication that discharge planning was particularly at risk of failing across regional boundaries. Gloucester shares a boundary with Wales and a professional carer who worked in one of the villages close to the border mentioned that, when patients were taken to hospitals in Wales, communication with English services to plan home support could be poor. Mrs S gave an example of an active pensioner who lived in supported housing and was cared for by her. He had an aneurism which was scanned on a regular basis and when it became enlarged he was admitted to a hospital in South Wales for an operation. When he was discharged there seemed to be no aftercare planned, as she described:

His daughters kept contacting me frantically because they were so concerned they were going to send their father home and there seemed to be no other agencies involved. So they sent him home, he never had no equipment or anything. His mobility was quite poor compared to how he had been and he couldn't even go and make a cup of tea and take it into his lounge and have a drink. And he was worried about his catheter as well. I called the district nurses in [the area] because I noticed he only had one night bag with him. They hadn't been informed so they came out and had to fill out a clinical incident form about it. (Mrs S)

Carers' concerns not recognised

Whether or not services were planned effectively, in most cases carers took on many extra responsibilities. Often husbands and wives were happy to look after their partners but sometimes they were asked to carry out procedures which they felt obliged to do but would have preferred not to, such as injections or catheterisation. Mr G, for example had already had to catheterise his wife for three weeks some years before when she had an operation for a prolapsed uterus. This time she was given the task of injecting herself with a drug to stop blood clots but when both she and her husband had difficulty she asked the local community nurse who agreed to do it.

Despite this reliance on external help, carers also felt that their lives were made more difficult by a lack of information or a failure to include them in decisions. On some occasions it seemed as though their concerns were being overlooked. Mrs R for example was looking after her 82 year old mother who lived on her own in a second floor flat. She had collapsed in the street and was taken by ambulance to hospital where it was discovered that she had a urine infection because she had not drunk enough fluids and was dehydrated. She was discharged after a few days but things did not improve, as her daughter explains:

As soon as she was left, we'd leave her with food and drink, she was not having a drink or eating while we were not there. Our main problem was the days I was at work, so I'd go off to work and try and ring Mum, 'Please go and get a drink in the kitchen' and it was just a huge worry because we would come home and know she hadn't had a drink, hadn't had anything to eat, until we got there in the evening.
(Mrs R)

So Mrs R rang the social services department and she said she found:

They couldn't help us because she was physically capable of doing it, but wasn't doing it, it was her choice she's not doing it and they couldn't help her. And I thought I mustn't fall out at this stage. But I thought if Mum could do it she would, because she is a very busy, busy person but something was making her not do it. (Mrs R)

However social services did give her a contact number at Age UK and she rang. Within a couple of days they had arranged for a carer to call, which Mrs R described as 'wonderful' because they could go off to work in the morning knowing that the carer would come in, get her mother up, give her breakfast and make sure she ate and drank. This home from hospital package continued for six weeks and during that time the flat warden also gave her the name of a good carer who took over when the care from Age UK stopped.

Mr T had a similar experience when he tried to ask questions about some of the symptoms his mother, who had Alzheimer's, was displaying. When his mother collapsed and went into hospital he said the information he received was 'nonexistent':

You ask the nurse and doctor and they look at you as if you've got the cheek to ask what is wrong with your own mother. Once she was out of hospital they were not interested, I found out later about the Alzheimer's Society. (Mr T)

He continued:

It's supposed to be a team effort. The fact that I'd been looking after her for 11 years counted for nothing. They couldn't give a damn about me. I mean they've got her interests at heart, I know that they were

just trying to make sure she's going to be properly cared for, but they don't take any of my views on board whatsoever. (Mr T)

It was important that health and social care providers were aware of the circumstances when the older person lived alone or lived with a spouse who also had health problems. At least two of those interviewed had experienced problems when both had been ill. In one case the GP was aware of the situation and arranged for the carer to go into hospital and booked her husband into a nursing home. In another case, the wife was expecting to still be having chemotherapy for breast cancer during the time her husband was booked to have a hip operation. Their son, daughter and two neighbours offered to drive them to their appointments.

7.2.5 Suggestions for improving services

The greater travelling distances to hospitals and health services certainly created problems for those interviewed and increased their reliance on family and friends but no one complained about this, perhaps because they were used to it. The improvements participants wanted to see in the services they received were more related to psychological and emotional factors than physical ones. These included greater involvement in decisions about their care, better information, and more considerate care to help relieve the fear and anxiety they faced going into hospital. Also better discharge planning was called for so that support was provided proactively and people did not have to chase this up when they returned home.

7.3 The implementation phase

7.3.1 Feedback and transition into implementation

The initial slow recruitment of participants meant that the first wave of interviews was only completed at the end of July 2011. This left little time to take forward any actions, as the project officially finished at the end of October that year. However, preparation for implementation was discussed with partner organisations and co-researchers at an All Sites Day in early July, and a process for involving local stakeholders commenced later that month. GOPA, Age UK and the co-researchers were particularly instrumental in discussions about the design of the feedback event. After three iterations, the outline design of the day was finalised and a preparation meeting was fixed for early September.

7.3.2 Negotiating the interventions

Twenty-six people attended the feedback event, with the majority representing voluntary, community, user and carer-led organisations (WRVS, Gloucestershire Rural Community Council, Gloucester LINK, Gloucestershire Older Persons' Association, Age UK, Gloucestershire

Association for Disability, Carers Gloucestershire). In addition, a number of committed Heads of Services attended from Gloucestershire Care Services (Older People Accident Prevention, Occupational Therapy, Reablement) and Gloucestershire Hospitals NHS Foundation Trust (Patient Experience, Old Age Medicine), together with representatives of Gloucestershire County Council Locality Services, and the three co-researchers. Unfortunately there was no representation from the local authority or health service commissioners, which was reportedly due to the major reconfiguration changes.

The event was designed in three parts: co-researchers and the research lead feeding back research findings; prioritisation of the most important actions that would have the greatest impact on service users' and carers' experiences; and identifying and planning local improvements. A number of major issues were identified as important for follow up including:

- Continuity of communication and information
- Appropriate use of language
- Joined-up services
- Having a care plan
- Access and transport
- Need for practical support
- Loss of identity – being a 'patient' rather than a person
- Recognising high levels of anxiety in patients
- Moving from ward to ward
- Understanding what happens when and why.

From this, three specific priorities were identified as areas that could be taken forward by those present, which would build on and support local work already underway:

- Implement an A.B.C. approach in services: Awareness and information (about the individual); Begin to plan on admission (transition, discharge, next steps); and Communicate (between different professionals and agencies)
- Communication and information between professionals and patients; focus on GPs and clinical staff (consultants and nurses), providing training based on real stories and using patient-centred approaches.
- Individual communication, with the guiding principles being 'do unto others as you would have done unto you' and treating patients, carers, family, and friends with dignity and respect.

7.3.3 Taking actions

Participants at the feedback event formed into working groups to take each of the above actions forward. One concern we had about the ability to progress this work was that the majority of those who signed up for working groups represented voluntary, community, user and carer-led organisations, while the work needed to take place within acute and primary health care settings. Also, while there was good participation and commitment from the local healthcare services, this wasn't from those in charge of the wards. However, there was energy and commitment from those present who were well networked so we decided to start with these members to maintain momentum.

The next step was to hold a local implementation surgery to support the further development of the ideas into concrete projects. This was a day designed with three two-hour sessions; each working group would meet with the OD lead to update, plan and progress the work. Unfortunately the surgery was cancelled, due to so many participant apologies given near the day, so an alternative date was sought. However as there had been a major delay in the recruitment of participants and co-researchers during phase one, we were unable to proceed with implementation as funds were not available to support the work after the scheduled end of project date. This created a lot of disappointment for the local stakeholders who felt that they had been promised support at the beginning and this was now taken away at a point when they were ready to work on making changes. They commented that this felt similar to the experience of local community groups where consultations and research was never followed through to impact.

In spite of the halt to this project, local players went ahead and worked to integrate findings from this research into existing services and developments. They did this in a number of ways:

- Gloucester LINK had already conducted a discharge survey with patients and findings from our report were very similar, so it helped to strengthen local priorities
- Gloucestershire Hospitals NHS Foundation Trust's Head of Patient Experience paid a lot of attention to the findings, in light of an inspection report from the Care Quality Commission that pointed out some limitations in discharge and other issues on the ward.

Gloucestershire Hospitals NHS Foundation Trust has started a number of initiatives:

- Instigating training with staff linked to new behaviour standards concerning kindness and respect
- Looking after older people round mealtimes with ward based volunteers supporting patients who are having difficulty eating and drinking

- Working with carers to develop a carers policy
- Creating information to help patients understand the discharge pathway and expected experience.

In relation to this last of these initiatives, local stakeholders working on this project have pointed out two areas that they feel have not yet been adequately considered:

- How people will find out how to access extra support to enable them to return home after an inpatient stay in hospital
- The provision of support to outpatients or people who are seen in accident and emergency but not admitted, who may also need support to return home.

Reports from local older people seem to indicate that the information for patients may not filtering down into practice, so will need continuing reinforcement. However, the Trust has taken a number of steps in relation to this research which merit positive acknowledgement.

8 Key themes and insights

8.1 *Cross-cutting themes from the research*

The opening section of this chapter summarises the main themes from the comparative analysis of the findings from the four case study sites.

Following this, we review these themes in light of the literature review and conceptual framework presented in Chapter 2 to explore how this study relates to and builds on the existing evidence base. Finally, the learning from our activities to implement the research findings into local policy and practice are discussed.

This study explored the experiences of different groups of older people, in different locations and circumstances, during different types of health and social care transition. Despite this considerable variation in the topic of investigation, what is striking about the findings is that the main themes from the experiences shared with us were remarkably similar. This is not to say that actual experiences were identical across the sample, but rather the data reveals that the needs, preferences and expectations which older people have in common are far greater than those on which they differ. A second general comment is that, even though the study set out to explore transitions, narratives were often dominated by experiences of specific services (e.g. home care), professionals (e.g. social workers) or within specific settings (e.g. hospital wards). Instead of seeing care transitions as discrete events, as services sometimes do, older people framed and understood them within the bigger picture of their overall experience.

Feeling orientated in a 'foreign land'

Participants' experiences of transition were frequently accompanied by a sense of disorientation. The new and unfamiliar circumstances that many people found themselves in could be environmental (e.g. being in a hospital ward); social (e.g. changes in spousal or parental relationships as one person assumed the role of carer); and/or related to identity (e.g. the onset of a degenerative condition such as dementia). More challenging still for some was uncertainty at what the future would bring: when and whether 'normal' life would be resumed. Given this, it is not surprising that difficult emotions were common and included fear, anxiety, confusion, loneliness and sadness. In these situations, people sought to make sense of what was happening to them, in order to cope with and adjust to their experience. Whether the transition they were undergoing was relatively discrete or likely to be ongoing, these sense-making activities were always in evidence.

Our findings show that communication had a vital role to play in this process, and participants placed a high value on being kept informed about their care or the care of their family member. Good communication made

people feel cared for and fostered trust and rapport with service providers; it enabled people to feel safe and connected in what was an otherwise 'foreign land'. However, participants across all four sites reported that important information – e.g. about diagnoses, assessment processes, test results and discharge plans – were not shared with them in a clear, transparent and/or timely way. This left people not knowing what was happening to them or what to expect, which could exacerbate anxiety and add to their sense of disorientation. Although some participants took it upon themselves to find out more, they didn't always know what questions to ask to elicit the information they sought. The way that service providers communicated was as important as the information that was shared. Some of the most negative examples recounted in interviews showed that communication that was not sensitive and empathetic could be as distressing as no communication at all.

Being recognised and valued as a person

Common to all of the groups of older people that participated in this research was a wish for services to recognise and value them as a person. This meant being seen as a human being with needs, wants and feelings, rather than as a problem to be solved. Research on patient-centred care defines this issue as 'seeing the person in the patient', a key element of which is treating individuals with respect and compassion (94). To this we would add that carers too want to be seen as a person in their own right – with physical, emotional and practical needs – not just in terms of the support they provide to the person being cared for. Our study confirms the importance of these interpersonal aspects of care; it also found that they exerted a strong influence on patients' and carers' views about the quality of the care they received. One of the most striking findings was that even the smallest gestures by providers to connect with somebody as an human being – such as a smile or a hug – could make a significant difference to their sense of dignity and their experience overall.

One way in which providers can acknowledge patients and carers as people of worth is to involve them in the care process, adopting approaches that are about 'doing with' rather than 'doing to'. Participants differed in how they spoke about involvement. Some, especially carers, explicitly called for services to include them in planning processes and decisions about the person they cared for. Many others pointed to the importance of being listened to and heard; they may not have sought to actively share decisions, but nonetheless wanted their views and concerns respected in any decisions taken. Irrespective of how 'involvement' was defined by participants, our findings clearly show that older people valued having a voice in the care process and that this helped to foster mutual understanding between them and the various staff and professionals they came into contact with.

Importance of informal support networks

A strong theme in many of the accounts that were shared in this research was the centrality of family, friends and neighbours in participants' lives. In many cases, family enabled participants to maintain contact and participate in social activities, in so doing reducing the risk of loneliness and isolation that older people can experience. Our findings indicate that this connection with significant others, which also included friends and neighbours, provided some people with a real sense of belonging and underpinned perceptions of wellbeing. Moreover, many people relied on family and friends – and above all on informal carers – for practical and emotional support, which in turn could help to promote independence. The value of informal support networks was highlighted in all sites, but this was particularly important for participants with dementia who relied on family and friends to help them adjust to living with dementia at a time when their whole identity (not just their care) was in transition.

Many participants, not just those who were themselves carers, felt that carers were often sidelined by health providers and support services. A number of problems were mentioned which suggested that providers did not always recognise the needs or expertise of families and informal carers. These problems included excluding or marginalising carers in decisions; not keeping them informed about important developments in their family member's care; failing to recognise carers' own concerns and support needs; and delivering services in a way that clashed with or undermined the efforts of unpaid carers. The last issue was mentioned by a number of participants, and indicates that receiving formal support services can be something of a mixed blessing. The best experiences involved services that worked with the grain of family relationships and informal caring arrangements, seeking to understand and complement these. Examples of this type of collaborative working with carers were found, but were the exception rather than the norm.

Services taking a planned and proactive approach

Transitions, both in care and in life more generally, are often unsettling experiences because they involve change and create uncertainty. Our analysis shows that older people gain reassurance during times of transition when they see that services are anticipating, planning and managing the care that they need. Such an approach can foster a sense of being guided and supported through transitions, with each element joining up so that there are no gaps to fall through. It also gives patients and carers an idea of what to expect next, so that they can prepare themselves for changes – whether that be physically, emotionally or in terms of making practical arrangements. Aside from isolated examples, we found little evidence of health and social care services consistently taking a planned and proactive approach. Far more common were experiences of stumbling across services, having to seek them out, or even in some cases needing to 'fight' for them.

Many factors are likely to underlie this problem, including one that was a recurrent theme across our findings: information provision. Older people

with dementia and their carers reported that information about what services were available locally and how to access them was rarely if ever provided proactively. Information at the point of discharge was also a major problem; many participants left hospital unsure about whether they would receive support or services back at home, or how to access these in the future should the need arise. This might account for the feelings of anxiety and abandonment that some people described having at this time. The extent of advance planning around the discharge process was another issue, and the accounts shared suggested that there was often a lack of clarity about when patients would leave hospital and how they would get home. This unfortunately could add to the sense of disorientation that people felt, which was described above.

Support based on needs, in the present and as they change over time

The importance of support in the lives of the older people that we interviewed cannot be overstated. While participants described a variety of specific support needs, there was also a sense that people appreciated having somebody generally to whom they could turn to if necessary. The language people used to describe this including having someone 'to fall back on' or 'to bat for you'. Older people wanted, and our findings suggest that they significantly benefitted from, arrangements that offered reliability and continuity of support. Getting to know somebody – such as a social worker, home care worker or voluntary sector caseworker – over a period of time did not just enable participants to develop meaningful relationships with people in service provision roles. Additionally, it meant that providers were able to get to know the individual, their circumstances and needs in ways that were essential for support to be provided flexibly and responsively on an ongoing basis. Both of these features, in turn, contributed to a feeling of being recognised and valued as a person.

Where such relationships had developed over time, people experienced support as a steadying influence which gave them (and their families) considerable peace of mind. However, the reality for some participants fell short of this. Poor continuity in care and support arrangements was one of the most frequently mentioned issues. People felt frustrated at having to explain themselves and their situation over again when greeted by a new provider rather than a familiar face. Problems with home care were also raised, including services being inflexible, unreliable and rushed. The impression gained from some interviews was of services organising around their own needs, rather than those of the person that they were supporting. In these cases, the possibility that support could adapt to meet changing and emerging needs was all but eliminated.

Perceptions and expectations can act as a barrier to seeking help

So far our analysis of the barriers that older people faced accessing help has focused on factors relating to how services are delivered and operate. In

addition, our findings indicate that the perceptions and expectations that older people themselves had could act as a barrier. Theories of help-seeking behaviour, which explore why need for services does not always predict actual uptake, are well developed in health and social care. A key factor they highlight is that older people show a preference for receiving help from people with whom they are familiar, and turn to informal networks before approaching formal services. There are also psychosocial issues including the wish to maintain independence and self-reliance, not wanting to acknowledge the problem for which help is needed and cultural conceptions of what assistance is it acceptable to use (95).

Our findings also point to a range of factors that explain why participants did not always recognise or act upon their need for external support. A strong preference for receiving help from family and friends was evident, particularly although not exclusively amongst participants from BME communities. However, not all families were able to provide an adequate level of support and be on hand should a problem arise, which could create anxiety about whether and how the older person would cope at home. In these cases, formal services may have been beneficial to fill the gaps in the informal network. Some participants with dementia did not realise they had a problem or did not want to openly acknowledge this given the stigma and fear around this condition. Difficulties getting clinicians to make a clear diagnosis of dementia could compound this problem. Negative perceptions of services could also be influential, and were shaped by previous personal experiences and external forces such as media coverage. For example, having a bad hospital experience left some people frightened about the possibility of needing further acute care at some point in the future. A number of participants talked about which hospitals in their area were thought to be 'good' and 'bad', with the suggestion that they would avoid the latter at all costs if a choice about where to be admitted was possible. Not all of the perceptions that participants had were problematic, and clearly some – such as the desire to avoid a hospital where a bad experience has occurred – are very understandable. Nonetheless our findings do suggest that further efforts to raise awareness of conditions and services, and combat any stigma that surrounds these, would be beneficial.

8.2 Understanding and conceptualising transitions

In this section the usefulness of the conceptual framework in helping to understand the experiences of participants will be examined. The framework had three main aspects. Firstly, the division into three different dimensions of transition; secondly the different stages of the transition journey; and thirdly the different systemic levels of analysis which correspond to different perspectives, such as those of the participant, the organisations providing care and health policy makers.

The concept of transition

The findings show that participants were experiencing much more than just a physical move across services or settings. In most cases their illness was creating transitions on different levels: 1) physical in bodily changes, as well as use of services; 2) psychological, with changes in their identity or sense of self, perhaps involving anger and frustration, fear, or sadness and loss; and 3) social, with changes in their relationships with partners, family and friends. Whilst the physical aspects of the transition were often a priority for service providers (e.g. dealing with the life threatening symptoms of a stroke or heart attack), the importance of the psychological and social aspects was frequently overlooked.

These different transitions were happening simultaneously and if circumstances made coping difficult in one type of transition then it was likely to have an effect on others. In this the findings concur with those of Meleis and colleagues (27) who concluded that transitions were often multiple and complex. This makes a simple model of transition with (i) an ending (ii) a state of limbo and (iii) a new beginning, not particularly helpful in the case of older people who are using health and social care services. It is likely that the adjustment required for a new beginning becomes a stage that has to be faced many times as chronic conditions go through different phases and people get older. In other words, transition is continuous and so adaptation has to be ongoing.

The conceptualisation of transition as a journey and the stages in the analytical framework of antecedent, trigger, entry, throughput, exit and consequences, was useful as a way of structuring the interview and to some extent also useful in analysing the interview findings. But it does not map a journey that participants recognised. In fact for many of the participants the experience was more akin to Bury's concept of 'biographical disruption' (30). However, this conceptualisation does have uses from a service provider perspective because it draws attention to ways in which services or interventions can be improved.

The psychological and social dimensions of transition

Given the fact that most of the older people in the study were experiencing psychological change due to their health conditions, it is perhaps easy to understand the feelings of fear and anxiety, disorientation and confusion which they expressed. These feelings are also typical of people going through the 'limbo' stage of transition as Kydd found in his study of delayed discharge from hospital (40).

One element of this change for many of those in the study was fear of losing their independence. This manifested in a number of ways, such as an ambivalent attitude to asking for help when it was needed, or reluctance to acknowledge a problem or use services. The way in which health professionals respond to and help older people to manage these feelings and emotions is clearly a very important aspect of care. Yet health and social care professionals can be affected by the same cultural stereotypes

and so act in ways that reinforce older people's fears about losing their identity and independence. A review by Secker and colleagues analysing the concept of independence is helpful here (96). Older people identified self-esteem, self-determination, purpose in life, personal growth and continuity of the self as important components, but the review showed how the actions of care providers could undermine these.

Our study suggests three main ways in which providers of health and social care services can help older people cope with the psychological aspects of transition. The first is to acknowledge, understand and respond to the emotions the older person is experiencing. A number of the participants mentioned that there were differences between staff/professionals. For instance, some nurses were warm and friendly whereas others did their job without connecting with them; they carried out the technical aspects of the job without relating to the person. Pinder's discovery about the very different perspectives of GPs and patients on making a diagnosis of Parkinson's Disease is relevant here (31). Health and social care professionals are working in pressurised environments with many different priorities and unless they are made aware of the importance that 'feeling connected' has for people undergoing transition, it may end up low on their list of priorities.

Meleis and colleagues found that feeling connected to health care professionals, who could answer questions and with whom they felt comfortable, was an important indicator of a positive transition experience (27). This was also one of the main findings of the systematic review of older people's and relatives experiences in acute care settings carried out by Bridges, Flatley and Meyer (86). Our study echoes these findings, with most participants placing a high value on being treated as a person, good communication and information. In the high-tech hospital environment, or the formal world of social needs assessment, the older person in transition can be facing a double attack on their self-identity. In these circumstances, care which ignores a person's psychological needs could limit their ability to negotiate the transition and improve their health.

The second way is to help people maintain (or develop) their feeling of self-determination by involving them in decisions. This involvement has a number of different aspects to it. For example Meleis and colleagues mention the level of understanding of 'the different processes inherent in diagnosis, treatment, recovery and living with limitations' (27). Ryan and Scullian report participation in decision-making as a factor contributing to a positive choice of care home (44). Sadly our study confirmed the findings of many other studies that, despite policy and legislation emphasising the importance of involvement in decisions, this is still not happening for many older people receiving care. One of the main factors preventing involvement was lack of information. Decisions often involve choices and for that older people require information at the right time. Our research showed that services were not planned in a way that delivered information when it was

needed. Instead participants came across relevant information in a haphazard way.

The third way is to help people develop the skills to manage or cope with their condition(s). Again Meleis and colleagues argue that a person's 'level of mastery will indicate the extent to which they have achieved a healthy transition outcome' (27). There are several different types of self-management and recovery based programmes that apply cognitive behavioural therapy (CBT) principles to help people with chronic conditions. However, none of the older people in our study mentioned being given information about one of these courses (such as the Expert Patient Programme) or any information that was based on CBT principles.

Our study also supported Meleis and colleagues' finding that the social dimension of transition was very important (27). Their proposition, that through discussion with family and friends the meaning of a transition and the feelings and behaviours that resulted were clarified and acknowledged, was upheld. In addition, in our study, family, friends and neighbours enabled participants to participate in social activities and helped them maintain their independence. Yet the value of this social dimension was often overlooked by service providers who sidelined carers, failed to keep them informed and did not recognise their concerns.

The levels of the health system

The final part of the conceptual framework, identifying the different levels of analysis from the individual to the health and social care system, is useful in helping to identify the barriers to effective service delivery. It is clear that relevant policy, such as the National Service Framework for Older People (1), promotes care that has an implicit, if not explicit focus on the psychological and social aspects of transition which this study has found important. For example it advocates a cultural change in services so that older people and their carers are treated with respect and dignity, and calls for services that are integrated across health and social care and support independence. However, the way this policy is implemented varies across the country.

The implementation phase in each of our case study sites illustrates the variation which is a result of the different arrangements between health and social care, and the way in which voluntary sector organisations work with them to provide services. The continuity of care that participants themselves wanted, in order to provide reliable support as they moved between services, clearly included the three main types of informational, management and relational continuity identified in many studies (97). Care seemed to work best when specific services to coordinate care or supply information were provided.

8.3 Working with local partners to implement research into practice

Experience centred versus functionalist approach

Our commitment to co-production and using a narrative interview method privileged an experience centred approach (98) over a functionalist one focused on services and service mechanisms. This approach does not provide the kind of instrumentality that many NHS and policy oriented studies prefer, and a challenge arises in seeking to translate complex lived experiences into tangible service improvements. The organisational, cultural and practical barriers that hamper the use of standardised patient experience data in healthcare quality improvement are well known (99). An important lesson from this study is that gathering experiences in the form of stories enhances their power and richness, but may demand even more careful and creative thinking to turn 'raw data' into concrete actions.

We chose not simply to provide a list of recommendations for sites to consider, because the methodological literature and previous experience suggested that linear, information-based models of research implementation were of only limited effectiveness. Instead, our strategy was to directly engage local stakeholders in identifying and negotiating changes to services. While partners were aware and supportive of this strategy at the outset of the project, by the time the findings were ready they were working in a far more uncertain and difficult environment. In some cases, this significantly limited the input of partners and other stakeholders (statutory and voluntary) into the implementation work.

One weakness in the design that had implications for the implementation phase was not interviewing staff. Had we interviewed staff in the services mentioned by older people, this may have enabled us to identify and engage practitioners and clinicians, and potentially given easier access to work with them directly on the changes identified by older people.

Research and implementation as separate study phases

Prior to designing this study, the research team were clear that, despite problems with transitions for older people being well documented, issues persisted on the ground year after year. Therefore any new research needed to help embed findings in policy and practice. To this end, our approach was designed to establish the active involvement of older people themselves (co-research) to provide a more detailed and nuanced evidence base to try and influence change at a local level, and provide support to bring about actual change on the ground (implementation). In response, we designed an iterative process (research followed by implementation), aligning this to the cycle of planned change, drawn from organisation theory (53), which we knew was an effective organisational development approach.

In practice, this ran the risk of splitting research from implementation, so the research team had to work hard at managing its own transition (see below for further discussion). We also experienced a number of delays in recruiting and training co-researchers, meaning that the bulk of our early efforts had to be focused on getting the research phase up and running. Ideally, and in a more settled policy context, we would have had more time and capacity upfront to begin the research and implementation concurrently, but in practice this was not possible.

Judging the time required for different phases

Change normally takes time. Change that is initiated externally, and which doesn't carry the power-coercive imperative (99) that is normally associated with policy must-do's takes even longer to implement (if at all) because local players need to be persuaded that there is something in it for them and that it will be helpful to them in delivering those things they will be scrutinised on.

Due to the recruitment of co-researchers and participants taking much more time than anticipated, the start of data collection in phase one was delayed, and this had a knock on effect on subsequent implementation by reducing the time available for this part of the project. Across the case study sites, the implementation phase had either recently begun or we were beginning to engage local players in planned activities as the project ended. For some sites this didn't affect the implementation work either because they were taking the research findings forward under their own service development programmes. However for one site it nearly stopped all the follow-on developments that had been planned, and we were grateful to the SDO for permission to continue working with this site beyond our initial deadline. For another site there was a degree of disappointment that follow-up support could not continue for as long as originally planned.

Managing the transition from research to implementation

Local Advisory Groups were seen as the 'transitional mechanism' (23; 77) for moving from the research phase to implementation, and took responsibility for organising the multi-stakeholder feedback events. In the beginning, it was envisaged that they would also plan and steer local implementation work. However, while local advisory groups did host the pivotal feedback event, they were not necessarily the right mechanism for steering the work thereafter, as some of the individuals and organisations that needed to be involved had not necessarily been identified in advance.

In reality, different processes emerged for implementing findings, including linking in with already established strategic groups or working closely with local partners that wanted to progress implementation more specifically. In the cycle of planned change (53) feedback acts as a tool for managing the transition from collecting information to planning action, modelling how to make sense of and work with information gathered/known about the system in a participative and inclusive manner. In our study, the feedback meetings

offered an important opportunity to engage and involve local stakeholders in identifying and agreeing local priorities to be taken forward. Nadler suggests that feedback is the essential component to planning interventions for organisational change, and that a number of different methods need to be employed (100). He also suggests feedback does not automatically create change as organisations often ignore feedback or don't make an effort to use it effectively.

The design of our implementation methodology initially suggested holding a multi-stakeholder event for feedback, focusing on the need to creatively engage local stakeholders with the stories of older people 'such that they couldn't ignore the findings' (100). While each site held one overall stakeholder event for feedback, in some sites the findings were presented several times to different audiences. With hindsight it might have been best to plan for 4-6 sessions of feedback to a range of strategic, management and front-line stakeholders to build intelligence of and engagement with the findings across the local health and social care system. Having said this, the number of feedback events did not appear to make a difference in terms of moving the work forward. What did make a difference was local leadership and project management, tangible activity and commitment.

In addition, stakeholders across all case study sites said that there were 'no surprises' in the feedback; they already knew the issues (mirroring what we had felt when writing the initial proposal) and these were the same issues that had been around for years. Because of this, and a wish not to duplicate efforts, local stakeholders wanted to embed implementation into existing initiatives. While this felt right, it conflated our findings with a much broader range of plans and activities, and this may have served to lose focus. The exception to this experience was in Manchester where specific findings, linked to a very focused area of service development, were selected to be progressed. That this project was also used as an opportunity to extend and embed the co-researcher model was down to values of key people at Manchester City Council.

9 Evaluation of the participatory approach

This research was committed to the active involvement of older service users, their carers and other key stakeholders at all stages of the research process. An analysis of their involvement in the study design, recruitment of participants, data collection, analysis and dissemination of findings follows.

9.1 *Impact on different stages of the research*

Design

The participatory approach did not extend to involving older people in the design of the research proposal but representatives from three older people's organisations (Carers UK, Age UK and the Alzheimer's Society) all provided feedback on the bid. The reason for not including older people in the design was largely one of timing and deadlines for the submission. However, interviews with academics suggested that more user involvement from the start of the project would have been beneficial:

I think we've designed a traditional research project and then added in the participatory approach. If we were doing it again I'd include service users from the start. (Research lead)

Recruitment

The recruitment of participants was initially undertaken by research leads and some delays were experienced that were frustrating for co-researchers and academics alike. Co-researchers reported that they lost some enthusiasm and momentum as their training took place some time before doing the first interviews. Not all co-researchers felt they were kept well-informed about the reasons for the delays.

The research leads were more used to the time required to set up research projects but were aware of the difficulties of their chosen approach. As a result, the co-researchers were also asked to recruit participants. Many of the co-researchers felt they should have been given this opportunity to take a more active role from the beginning because of their extensive knowledge of local networks and their ability to 'get the word out.' In the end, some co-researchers referred people they knew personally which then caused their academic partner to worry about the ethical issues involved in interviewing someone you know.

Data collection

Much of this evaluation focused on the role and impact of co-researchers on data collection, as this was the stage at which the co-researchers had most input. Without exception, the main benefit reported by the co-researchers

of their involvement in the interviews was that they put participants at ease. For some it was due to the informal, conversational style they brought to the interviews:

I got the impression they talked more freely with me than they would with [the academic researcher] who had all the paperwork to complete. I think they regarded her/him as an official. (Co-researcher)

For others it was their proximity in age to the interviewee:

I think they look at us and see we're closer in age and think they haven't sent a young whipper snapper to talk to us! (Co-researcher)

Where the interviewees were people from minority ethnic groups, having a shared language was very important:

When they spoke in their own language, they felt comfortable to talk, they feel at ease and want to talk to you. Professional translators would not have been the same. (Co-researcher)

In this site the research lead emphasised the role of the co-researchers in facilitating access to voices which otherwise would not have been heard due to language and cultural barriers.

Many of the co-researchers talked about how the interviewees valued their shared experiences:

We might just know the precise question to ask to bring out the information. (Co-researcher)

Sometimes the carer would say 'Did you find that?' and wanted to know what we thought. (Co-researcher)

One research lead considered that:

The closer you are to the person you are interviewing the more insights you have. (Research lead)

Therefore, older people with an experience of hospital or dementia services could bring an advantage as they might find it easier to develop a rapport with the interviewee and understand what they were going through. One co-researcher with dementia felt they helped the interviewee communicate more effectively:

I was able to...reach out. (Co-researcher)

The research lead in that site made a similar point:

In one situation I was struggling to make myself understood and get across the point that I wanted the person to focus on. [Name of the co-researcher with dementia] was able to do that in a way I wasn't able to do. (Research lead)

However, one co-researcher was not convinced about the need for personal experience but rather the capacity for empathy:

[The research lead] is very empathetic and I believe they can fully understand the needs of the carers and users. Sometimes having had the experience can hinder the process. You come with your own personal baggage and that has to be dealt with. I'm not entirely sure that [the research lead] couldn't have done this without us. (Co-researcher)

Some co-researchers struggled between their role as a researcher and as an older person/peer. In the first evaluation interviews, some of the co-researchers expressed their eagerness to share their knowledge with the participants and anticipated that they might be able to advise and help them. However, when they carried out their interviews most of the co-researchers were acknowledging that this was not their role, however difficult that was to sustain:

It was difficult though because we were there to ask questions, not there in an advisory capacity or to help...Sometimes I would have liked to help and give advice but we weren't there to do that. (Co-researcher)

So whilst there was almost unanimous agreement about the ability of the co-researchers to make the interviewees feel at ease, there was less agreement about the impact they may have on the quality of the data. This includes a potential tension between the data generated by the co-researchers in the interviews and the data that is required to answer the research questions. Research leads commented that they did not feel the co-researchers always had the skills to pick up on significant issues and explore them in depth so, in some cases:

Some of the issues that surfaced were left hanging. I was left thinking you need to pursue this. But I never interrupted. (Research lead)

Analysis

The experiences of co-researchers in the analysis of data varied between sites but overall, they were less involved in this stage than in others. However, in each site, the co-researchers were involved in the selection of interview quotes for the feedback events. There were some clear benefits to involving co-researchers in the analysis as they were able to provide context to and interpret the findings, as the carer of an older person with dementia reflected:

Partly to do with the experience we're all going through, perhaps you're able to judge the authenticity of what other people are saying. You can say 'Yes, this is what happens', a researcher could note it but someone who has experienced it puts a different understanding on it. (Co-researcher)

One research lead recalled how they and the co-researchers had informally reflected on and discussed each interview as soon as it finished (for example in the car afterwards). This was part of the analysis process as co-

researchers were able to interpret the interview data immediately, especially around cultural or other contextual issues.

The final report for the research funders was written by academic research team. One research lead felt that the inclusion of co-researchers in data analysis and reporting is something that is frequently missing from participatory research and whilst there was some involvement in this study, it could have been better thought through when the project was designed.

Dissemination

The use of co-researchers was felt to have had a very positive effect on the dissemination of results to date, especially at the feedback events which were considered a huge success by the research team. Using the co-researchers to present the interview data was found to add value to the stories giving them a more 'lived experience':

Co-researchers being involved in the [feedback] event gave it a different feel to what you would have if you had us at the front doing powerpoint presentations. (OD Lead)

The co-researchers were also able to draw attention to the key issues, which were often considered to be very small 'micro' issues, such as staff attitudes, that can be solved without significant cost implications, rather than 'macro' issues, such as big service changes that require significant time and resources:

Things could be improved by some small things like asking the carer and person with dementia separately how things are or nursing staff recognising that people have dementia and helping with feeding and drinking in hospital. (Co-researcher)

One research lead explained up the effectiveness of their partnership:

The combination of me and them [co-researchers] seems to be a bit of a magic bullet in terms of impact. I do worry that if it was them on their own, their ability to access the key people in health to present to, at boards etc...they don't operate in those sorts of environments. Me on my own in those environments would have been ok, but me with them is like a magic bullet because I can set those meetings up, I have that understanding of the world people work in, but they bring something that I can't, this research is all about experience, it's all about people. Me standing up in front of a group of people saying this is what we heard, has no comparison to them saying it in the person's words. Together we are quite a potent combination. (Research lead)

9.2 Impact on stakeholders

Co-researchers

The overwhelming motivation for co-researchers to participate in this study was the desire to improve services, resulting from their own experiences as both users of services and carers. One carer summed it up:

I hope there will be a good outcome. That's what motivated me, things being so difficult for us. (Co-researcher)

A few people recognised it was a way to meet new people, feel useful and 'give something back', whilst others identified personal benefits for themselves including the chance to develop their skills:

I've realised I'm some use to society after all, even at my advanced age. (Co-researcher)

It opened up my world, associating with other carers. (Co-researcher)

At the time of the second interview, co-researchers were not disappointed in their involvement and without exception, they all had enjoyed being part of the research. They all commented on their good working relationships with the four research leads and attributed much of the success of the study to their enthusiasm and competence.

The voluntary organisations all felt that the co-researchers had gained skills and knowledge as a result of being involved and had widened their horizons. One co-researcher had been offered the opportunity to be on a national reference group as a result. Other people felt the knowledge they gained would be useful to help themselves, or others, negotiate the challenges of ageing:

The whole process gave us a lot of information that we did not possess at that time, which we can now apply to other people within our groups. (Co-researcher)

Academics

Members of the academic research team all entered this research project motivated by the innovative approach but anticipated that it would be challenging. They acknowledged that the study was an evolving process and that they were learning as they went along. The key issues faced by the research and OD leads were:

- The complexity of the project with the number of different stakeholders involved
- The sensitivity of some of the ethical and organisational implications of the participatory approach
- The need to keep co-researchers informed about the progress of the study
- The importance of negotiating the role of both the statutory and voluntary organisations and trying to engage them throughout the process

- An uncertainty at the beginning of the study about what kind of knowledge would be produced as result of the co-research model
- An awareness that they had to reassess and relinquish some of their power within this process if the co-researchers were to be anything more than their research assistants.

The leads in all four sites had enjoyed the experience of working with co-researchers and had been impressed by their skills, enthusiasm and commitment to the study. They all acknowledged that working with co-researchers had taken significantly more time than had they done it alone and that time was needed to develop good relationships with the co-researchers:

You have got to have some trust and friendship, and you have got to feel comfortable with each other. You have got to be able to pick up on people's body language and nuances, and you can't do that unless you know them reasonably well. (Research lead)

As the section above on data collection indicates, the research leads sometimes had to curb their urges to intervene in the interviews and trust that the data the co-researchers collected would meet the research aims.

The research leads all indicated that they had difficulties establishing effective partnerships across organisations. Whilst they all spoke of good relationships with the voluntary agencies, and in some areas with the statutory agencies, they felt these ran along parallel tracks rather than being part of an integrated system. The OD leads also felt some frustration with getting key stakeholders equally involved in the implementation process. They felt that they (both OD leads and stakeholders) could have been more involved from the data collection stage:

Research and change at the same time so that you don't have to wait such a long time, by which time the world has moved on. People get the benefit of that very quickly. Small interventions on an ongoing basis. (OD lead)

Issues around the challenges of engaging stakeholders are taken up further in the discussion on barriers to implementation and change.

Voluntary organisations

The five voluntary sector LPAs involved in the research study were very enthusiastic about their involvement. They were aware of the negative experiences of transitions between services that older people in their localities had experienced, and in all sites felt the research was timely. In all the sites they felt older people were very actively involved and that the participatory element of this research fitted well with their work around trying to develop the capacity and confidence of older people. This research was a way of getting:

Carers and older people at the heart of decision making. (Voluntary organisation)

In two of the sites, the voluntary sector LPAs felt the research study had been an effective catalyst in getting the statutory and voluntary organisations working together:

There was no choice for the statutory sector but to sit and listen for much longer than they normally do. (Voluntary organisation)

In the other two sites such dialogue had not happened because of the degree of change and reorganisation which was taking place at the same time as the research. As a result, the voluntary agencies perceived the statutory agencies as uninvolved in the research process. Some voluntary sector LPAs saw an important role for the co-researchers following this research to be able to hold the service providers to account:

I hope they'll be able to say 'Come on [statutory agency], what have you done? (Voluntary organisation)

Statutory agencies

The three representatives interviewed from the statutory LPAs at the beginning of the study were unanimous in their enthusiasm for this timely research. All of them acknowledged the importance of seeking the views of people who use services in influencing their design and delivery but their failure in the past to make this involvement meaningful:

It's been so useful for telling us how it feels for a person accessing services. We think we know what they need, what we need to commission but that might not be what people want or people actually value. (Statutory agency)

At the end of the research study, change and re-organisation of personnel meant that only two of those people were re-interviewed. They were of the view that, despite the small number of older people interviewed, the results had been useful in highlighting the difficulties that people had in accessing and using services. The pressures of other priorities meant that they had not been able to give as much time to the project as they might have wished, the effects of which are identified in the barriers to implementation.

9.3 Impact on implementation and change

The aim of this evaluation was to focus on both the effects of the participatory model on the research (process), and on the changes to services the findings might bring about (outcomes).

Outcomes

The implementation phase of the research remains at a very early stage and work is ongoing. All interviewees considered change was more likely at a local rather than national level with research findings feeding into larger

change processes, including existing consultations and initiatives. Furthermore, the findings from this research were not considered 'revolutionary' but instead:

They have made a bit of a difference. Pieces of work are going on locally, especially in the hospitals, that we have been able to tap into and share the findings. Largely they reconfirm what they already know. (Research lead)

The specific impact of this research study is therefore difficult to assess as one research lead explained:

There is work being done as a result of the Healthcare Commission report on vulnerable, older people in hospital and our findings will ride on the back of that and add more weight to that. Previous research has been done and we are just part of that ongoing impact...So it's difficult to measure but it is inevitable that it will have an impact. (Research lead)

One interviewee from a statutory LPA felt the findings were even more relevant than when the project started as the imperatives for health, social care and other agencies to work together were now more pressing and it was so important to know about patients' experiences. However, in one site it was felt the planned changes in service delivery were insufficiently advanced for these findings to have an effect and, as such, their impact could be lost:

But they are not ready, they don't have mechanisms to do that. I'm not very optimistic unless we can give them a lot more time within the life of the project. (Research lead)

Process

Whilst changes to services were perhaps difficult to specify at the time of the evaluation, interviewees identified changes that they attributed to the participatory approach. As identified in the previous section, the prime motivation for co-researchers to take part in the study was to 'make a difference', which made the research team and LPAs more accountable and therefore motivated to ensure change occurred. The impact of the co-researchers' accounts were described by one research lead:

I was very surprised about the impact of these stories. Because I assumed that people would have listened to it before...The difference is because someone independent had written them down. (Research lead)

This was confirmed by the perspective of one statutory lead:

Some of our old ideas are a bit tired, paper surveys, customer satisfaction questionnaires. (Statutory agency)

This interviewee attributed the quality of the findings to the in-depth nature of the interviews and, as such, they would rather:

Go for depth and quality...than quantity. (Statutory agency)

In contrast there were comments from each of the sites to indicate that people who were not closely connected to the study found it less credible because of the small number of participants.

There were some clear benefits for the change process in involving the co-researchers in the feedback days and the co-researchers themselves saw a value in being able to talk directly to service providers. They felt their way of 'telling things as they are' had some advantages:

There's a lot of politics in academic and council meetings but what we are, are straight talkers. (Co-researcher)

Another interviewee, from a statutory LPA, felt that service providers sometimes only wanted to hear about positive experiences and these accounts had been 'a stark reminder' of more negative aspects of services. The participatory approach and use of co-researchers was seen as a clear benefit of the research and an idea that could be expanded for use outside of an academic context. As one of the OD leads observed:

Another bit of the council is now getting interested in narrative interviews as an alternative way of collecting data. It is like ripples, it is starting to have a bit of influence. (OD lead)

There may also be opportunities for the co-researcher model in monitoring, inspection and regulation of the whole health and social care sector. A lead in a voluntary organisation said:

I am talking to the CQC about the possibility of using co-inspectors in care homes because they will be able to get information from residents in a way that no external inspector could. (Voluntary organisation)

There is also the possibility for some of the co-researchers to continue in their role. In one site there are plans within the local authority for co-researchers to continue work on another research study, involving the employment of a local coordinator. In other sites there was no mention of any further work for the co-researchers but some certainly indicated they would be open to further opportunities once this research comes to an end. The success of this research study in trialling an innovative participatory approach was summed up by one research lead:

For me the benefit of this has been a methodological project rather than finding out new things about hospital discharge. (Research lead)

9.4 Factors helping and hindering

Factors helping

Many of the factors that contributed to the success of the participatory approach revolved around the effective working between the academics and the co-researchers. There was evidence of mutual respect and trust between them in each of the sites, as there was between the members of the research team at the University. These good working relationships were attributed to the amount of time invested in establishing trust and understanding. The calibre of the co-researchers was remarked upon by many people and one manager concluded that, in their site:

Their sum is greater than the parts. (Voluntary organisation)

Most of the co-researchers reported that they had been recruited personally from within their volunteering network, causing one academic to worry that we may simply have recruited 'existing activists'. However, as the research project progressed this transpired to be a strength as the co-researchers were very proactive in bringing about change within their local area, including through their own networks and forums.

Good research skills training was an important positive factor identified by all the co-researchers. For those who had not undertaken any research before, training was an opportunity to learn new skills and try them out in a safe environment. The Research leads saw it as an opportunity to get to know the co-researchers better and to work with them on finalising the approach to data collection. One group of co-researchers confirmed the value of the collaborative approach:

[The research lead] has taken on board what we have said as we've gone along and used it to make improvements. (Co-researcher)

The involvement of the voluntary sector from the start was identified as crucial to the success of the study, particularly as critical links to the local community and for their role in identifying potential co-researchers and participants.

Factors hindering

All parties involved in the research experienced frustration with the slow start to the data collection. This was largely due to delays in acquiring ethical approval and difficulties in the recruitment of both co-researchers and participants. Despite a series of reported and potential changes as a result of this study, the research team also faced a number of significant challenges with the partnership model. The main problem has been sustaining the relationship between the different stakeholders in the project. Engaging the statutory sector was key to ensuring that change occurred but in some sites this proved difficult:

The voluntary sector partners just don't have power in the system. So they will say that it is down to the commissioners or hospital management because they are the ones that can make a difference. (OD lead)

In all of the four sites, the lack of an effective local advisory group was identified as a key hindrance, especially during the implementation stage:

We were ok working at the grassroots, we were getting the information together, but there wasn't a similar and parallel activity at the top level. I feel that it would have been better if we had someone at the top who was following our progress. We reported on what we had done but it wasn't ongoing. It would have been useful for that advisory body to be active all the way through. (Co-researcher)

The failure to sustain the involvement of the statutory sector was particularly highlighted in two sites and a number of reasons were identified for this. As mentioned above, the findings from this research served to reinforce what people already knew, which meant that the data was used to feed into existing pieces of work rather than to implement anything new:

My hunch is that they are seeing the evidence and saying that is what we expected and we are already doing this and that...They had already started implementing things. The findings probably have fed into existing consultations. (OD lead)

The change of personnel and restructuring of statutory agencies was identified as a hindrance for good partnership working in three of the four sites. Even where there was a least one consistent person involved in the research, capacity issues and other priorities were mentioned as difficulties. The current economic climate and public sector cuts were reported as significant barriers to implementation and change, for both statutory and voluntary sector LPAs, in all of the sites. As one voluntary sector lead said:

Our original optimism has become a mood of gloom. It's still too soon to know if we'll be able to achieve our original ambition to make transitions work better. (Voluntary organisation)

All interviewees from the statutory and voluntary sector were aware of the significant amount of time that they had invested in this research project. One voluntary agency in particular was aware of how it had impacted on other areas of their work and whilst they were happy to be involved and 'go the extra mile', realistic financial reimbursement would be a factor in any future research.

One statutory lead felt that there were some tensions in different working practices between the University and the 'field'. In particular, the pace of change in academia is very different from in their own agency where they need to constantly keep pace with decreasing budgets and they:

Can't wait for the results to come out in six months time, we need to use them locally now. (Statutory agency)

As a result, that statutory LPA would have preferred a smaller, shorter and more focused study because, although they were looking forward to hearing results from other sites, they felt they were of little relevance.

9.5 Summary of evaluation findings

The findings from the evaluation suggest that the participatory approach as embodied in the co-research model worked best in the data collection and dissemination phases of the research study. There was general agreement that having older people as co-researchers was beneficial for creating a comfortable environment in which older people could share their experiences of transitions, knowing that the interviewer had some understanding of what they were going through. It is difficult to attribute the quality of the data solely to the presence of the co-researchers and to speculate what kind of data would have been generated by academic researchers alone. However, there was unanimous agreement that having the co-researchers involved in the feedback events was a very powerful way of enabling service providers to hear the messages from the research.

The involvement of the OD leads in the dissemination of findings was clearly valued by service providers and there was evidence of some small local changes arising from the research but, more importantly of it feeding into other research and service redesign. However, the research and implementation phases had not been as streamlined as the original research design proposed and the partnership between key stakeholders was not as robust as had been envisaged. As one voluntary organisation lead concluded:

That's not to say that the findings are not being implemented and that the information and messages are not moving forward, they are, but it is not being done in that collective way that was always intended.
(Voluntary organisation)

Nevertheless, in all sites the co-research model was recognised as being a different and effective way of hearing the voices of people on the receiving end of services and in some areas the legacy of this model continues in ongoing work. Indeed, one statutory lead felt that the format of the feedback days could be used again in the future, once some changes in services had been put in place:

What we need to do is keep coming back to something like this, get a sense when we start to put things in place...so we can check out, do people see the difference, can they feel the difference? (Statutory agency).

10 Limitations, implications and recommendations

This study – drawing significantly on a co-research model and attempting to embed findings in practice – reveals a number of overarching themes about older people's services. Following a series of high profile scandals concerning the care of older people, these play into a broader debate about dignity, compassion and the treatment of older people in health and social care services. Indeed, with permission from the SDO, we have contributed emerging findings from this study to the 'Dignity Commission' set up by Age UK, the NHS Confederation and Local Government Association which has explored what changes are needed to deliver dignified care to older people in hospitals and care homes (100). We have also been working with nurse leaders to connect our experience of co-researching with older people with their work around improving the quality of nursing care and recognising care work as a form of emotional labour that needs appropriate leadership and support (101). However, while this project is of wider significance, this final chapter returns to our initial aim and brief. It considers the limitations of this study, considers the implications for future research and finishes with a series of concrete recommendations for improving older people's experiences at key stages along the care pathway as well as during the points of transition between them.

10.1 *Limitations of the study*

As with all research, this study has limitations which should be acknowledged. The first limitation pertains to the generalisability of the findings beyond the four case study sites. The sites were not selected to be representative of health and social care communities in England, but rather were chosen using a purposive approach that sought to identify areas with specific population characteristics in order to focus on groups that had been largely overlooked in previous research. While this narrowing of focus can be justified from a research design standpoint, it nonetheless raises a question about how context-specific the findings are, and whether more general learning about older people's experiences and service delivery can be drawn. As we note in Chapter 8, there was a high degree of similarity in terms of the central themes of the experiences shared. This suggests that there are many aspects of services and support that older people value irrespective of where they live, their cultural background or their particular health needs. With this in mind, we would suggest that the outcomes of this study provide useful insights to all organisations providing services to older people, not just those in the case study areas.

A second consideration relates to the perspectives that were accessed through the research. We sought to explore care transitions as a lived experience, involving in-depth interviews with older service users and carers. This can be seen as a strength of the study, inasmuch as our literature review found that previous research had tended to approach transitions from an organisational or systems perspective, which overlooked the perceptions of the person 'in the process'. However, we also recognise that the perspectives of staff within health and social care services are important too, and have much to offer with regard to understanding care transitions and how they can be improved. This study did not formally access staff views, nor were these triangulated with the patient experiences that were gathered. However, a range of local stakeholders did attend the local feedback events and helped to frame the findings in a broader organisational and policy context that was essential to the process of implementation. Some of the views shared at these events have been included in this report, but these are not intended to constitute a definitive staff perspective.

An aspect of the research design which may attract methodological concern is the method of co-researcher and participant recruitment. The use of voluntary sector organisations and networks might be seen as leading to biased samples that mainly comprise of older people who have taken action to be more informed, supported or engaged. Were this to be true, the accounts shared by participants in this study could represent the more positive end of the spectrum of experiences. Given the range of problems and issues we heard about, this is a sobering thought. However, as voluntary sector organisations have moved further into mainstream service provision, they have begun to access a much wider range of people than previously in their traditional advocacy and campaigning roles. Furthermore, efforts were made to reach different populations to avoid having self-selecting samples of 'highly engaged' patients and carers. In the Leicester site, for example, co-researcher involvement led to the recruitment of ten people who did not speak English as their first language.

A fourth and final issue concerns the selection of transitional types. An early aspect of the participatory approach was that the local sites selected a particular care transition to be the focus of the study in their area. The outcome was that three of the four sites selected the same transition: going into and leaving hospital. Sites chose this transition for different reasons, but in each case the decision was driven by the wish to extend or complement existing work. Whilst this limited the scope of the research in the sense that it only included two types of transition, our approach also played an important role in developing local ownership of and support for the study.

10.2 *Implications for future research*

Our report has shown that, despite increasing recognition of the value of involving co-researchers in research, there is as yet little evidence of formal evaluations of this approach. It is therefore important to outline for future debate some considerations which have arisen from our study. However, it is equally important to recognise from the start that there is no one way to effectively involve older people as co-researchers in research – the key to success is a commitment to working together and a flexibility and willingness to adapt and negotiate around more traditional ways of working.

One of the explicit aims of this research study was to include the voices of older people who are seldom heard and who are most excluded from public life. In our experience, recruiting co-researchers who were active amongst those groups and who had good networks in the community helped with the recruitment of participants was critical to the success of the project. This benefit must be weighed up against the potential bias or conflict of interest that recruiting already active citizens might bring.

Our study confirmed the findings of other research that having older co-researchers involved in interviewing helped participants feel at ease and that it was helpful for the person doing the interview to share some characteristics with the interviewee. We concluded that co-researchers are therefore particularly helpful if there are few commonalities between academic researchers and participants, but might be of less significance when there are shared characteristics and experiences between them. This finding suggests that co-research may be a particularly valuable approach where the involvement of more socially marginalised or vulnerable groups is sought.

What is less well documented in the literature is the role of co-researchers in analysing data, disseminating findings and implementing change. The involvement of the co-researchers in recounting the experiences that had been shared during interviews gave a power to the findings which, from our experiences of feedback days, would not have been reflected in the written word alone or in the delivery by the academic researchers alone. Co-research models of working lend themselves to more imaginative ways of disseminating research outcomes which must be considered at the stage of submitting the proposal. Thinking creatively about how the messages from research can most effectively be communicated to different audiences is a task that academic researchers and co-researchers can productively address together.

As it was, in this study, only once the funding had been secured did we involve the co-researchers in all subsequent aspects of the research. This breadth of involvement was not just driven by the research team's values of participation and co-production. It was both central to the fulfilment of our research aims and to meeting the expectations of the co-researchers (who wanted to be seen as research partners and not just 'data gatherers').

However, if these two criteria are not met then high levels of involvement in each stage of the research project may not be a desirable or attainable objective. Having a range of activities and roles that co-researchers can effectively undertake is an early consideration in any research planning process.

In this, as in other studies, good training and support was key to the successful involvement of co-researchers. Not only was it critical for the purpose of developing their technical research skills and enabling them to shape the research process, but also for the opportunity for learning not simply to be a one-way process. In this model of research it is essential that academics are prepared to assess and re-assess their positions of power in relation to co-researchers and be prepared to learn from them. Opportunities for trust and respect to develop are therefore necessary to enable effective partnership working. The involvement of co-researchers is time and resource intensive and the time to establish and maintain meaningful collaborative working is frequently underestimated. Research proposals and research funders must acknowledge this explicitly if the benefits of the model are not to be compromised.

The findings from this research study are not particularly new – we were told this consistently by both our local partners and co-researchers, some of whom had experienced the shortcomings of services themselves in relation to care transitions. Might the direction for future funding be to focus resources on studies that seek – as we have – to change, not just to understand, existing ways of working? This might necessitate greater use of innovative methodologies such as action research, participatory learning and developmental evaluation. A salient feature of these methodologies, and something which distinguishes them from the design of this study, is that findings are produced and shared on an ongoing basis to support cycles of reflection and action, rather than being seen as an end product of the research process. This approach may help to address the challenge that many health and social care researchers are currently facing: namely keeping up with the pace of change in the current policy and practice environment. Our experience was that, in the time taken to carry out and analyse the research, there had been substantial change in local structures, organisations and personnel. Given that change is likely to be an ongoing feature of health and social care services for some time yet, the time lag between starting a piece of research and the availability of findings could have considerable implications in terms of its relevance and impact.

Finally, we heard from the participants of the many small scale changes in practices which could positively affect their quality of care. Front-line practitioners, middle managers and strategic directors need to hear what these are and respond to them by asking the questions how could we do this, what's stopping us, what are the challenges, what resources and support would we need, what differences would we require in our organisations? This could be a way to achieve more lasting changes in local

service delivery and organisations which make a real difference to the experiences of older people and their carers.

10.3 **Recommendations**

One of the most important implications of our findings is that the way older people are treated by staff has a considerable impact on their overall experience. This is by no means the first study to conclude that improving the quality of services, as they are experienced by those who use them and their families, requires greater attention to the interpersonal dimensions of care. Most of the suggestions participants made for improving services called for 'micro-changes' in the care environment and in care relationships (e.g. better communication and information). There was very little suggestion that what was needed was new or different services; easier and earlier access to existing services emerged as a far greater priority. While these micro-changes may not cost large amounts of money, they do require committed and sustained effort to challenge existing ways of working that may be deeply ingrained in organisational and professional cultures. The question of how to bring about a more person-centred culture in health and social care has long been debated. Both as a contribution to that debate, and to draw out the practical implications of this study, a series of recommendations for health and social care practice are outlined below.

Care in hospital

1. At the heart of a good hospital experience is being valued and treated as a person, but pressures on wards and moves to drive down length of stay can limit opportunities for staff to get to know their patients. Patient-led initiatives, such as The Alzheimer's Society's 'This is Me' leaflet could offer a way forward. The leaflet is designed to capture and make available important information about a person with dementia when going into hospital, prompting for personal as well as practical details. In the case of an emergency admission, the leaflet could be completed by family members and/or friends, which may also help to more fully involve significant others in the care process from the outset.
2. The main caring relationship in hospital is likely to be with a nurse, and therefore any recommendations concerning interpersonal care have substantial implications for nursing staff and leaders. Blanket calls for improvements in nursing care standards fail to address what nurses themselves may need to better care for people at vulnerable times in their life. Recent research has pointed to the value of systems – such as the Schwartz Centre Rounds – that acknowledge and support nurses with the emotional labour of care (101). Such systems should be given serious consideration by acute healthcare providers.
3. Communication with, and the involvement of, family carers and members is an area in need of improvement. This raises a question about how involvement can be achieved given existing pressures on

professionals' time, especially where families are large and/or their dynamics are complicated. In the United States, the organisation Planetree has pioneered a model of family involvement called 'Partners in Care' which could be adopted within the NHS. A Care Partner is nominated by the patient, and invited to participate in various aspects of the care process and act as the family spokesperson.

4. Access to interpretation services for people who do not speak English must be seen as an essential precondition of safe, effective and humane care. If it not possible to always have an interpreter physically present during important times, then telephone interpreter services such as Language Line should be available as a standby option.
5. Achieving all of the above requires leadership and commitment at Trust board level. This study, and in particular the experience of our local feedback events, has demonstrated the power of patient stories. The idea of starting board meetings with a patient story has been suggested elsewhere (102). This and other mechanisms for bringing senior executives closer to the patient experience (e.g. ward walkabouts) could play an important role in supporting the development of more patient-centred cultures.

Diagnosis and support for people with dementia

1. There is considerable scope to further challenge the stigma of dementia so that people are more willing to talk about their problems and seek help earlier on. One of the most effective ways of countering negative public perceptions may be through the involvement of people with dementia themselves. As the experience of our co-researchers showed, this can also help to build confidence and maintain social skills for the person with dementia.
2. GPs are invariably the first point of formal contact when people are concerned about possible dementia. They need to be better informed about dementia, how to communicate with patients about this and how to connect people to relevant support services. The linking of dementia advisors to GP practices could play a key role here.
3. Professionals need to be aware that the manner in which they deliver a diagnosis or information about a condition affects the way that person perceives and responds to it. Consideration needs to be given to who is the most appropriate person to deliver this information; it may be that dementia advisors, who have more time to spend with the person, are better equipped for this task.
4. People who need services should not have to battle to get them. Every service provider on the front line of receiving requests for help should be trained to offer a supportive response, not to 'bat people away'. This may involve explaining to people why a service is not available or why they are not eligible for it, but it should be done in a

constructive way that leaves the recipient feeling clear about the situation and valued as a person. If contact needs to be made with another agency, the service provider taking the initial call should take responsibility for following this up, rather than leaving it to an older person to navigate their way through the system.

5. Worries about how they will cope in the future add to the anxieties of people with dementia and carers. Being clearer about the support that will be available if and when it is needed in the future will help people to cope with their present situation.

Managing transitions

1. People value and benefit from having one key person who can link them with other services and who is there to support them when they need it. For older people undergoing any type of transition, the nomination of a key person who will provide continuity of support and act as a link to other services would address many of the difficulties identified by older people in our study.
2. For older people with dementia and those with ongoing health difficulties, life involves continuous change. Service providers therefore need to see the management of difficulties as an ongoing process and be flexible to respond to changing needs. If their role and responsibility only relates to a small part of that process, their own actions nevertheless need to be taken in the context of understanding the longer-term process.
3. Advance notification and preparation play a vital role in helping people to manage the emotional and practical aspects of transition, and to exercise some control over the process. Participants varied in their desire for involvement in decision making at times of transition, but all wanted to be kept informed about what the likely next stages of their care would be and the anticipated timeframe. Effective communication includes communication about uncertainty.
4. Closer integration of services – especially across health and social care – would have a considerable positive impact on older people's experiences of transitions. Recent discussions have pointed to the importance of incentives and financial mechanisms to support the development of more integrated models of care such as pooled budgets, 'Year of Care' models and combining payments to cover entire episodes or pathways of care (103). Leadership at national, regional and local levels needs to address how integration can be not only encouraged, but also enabled.

Home and social support

1. Older people with ongoing health issues such as dementia try to 'make the best of it' and keep going as best they can. Services should try to support these efforts, not undermine them. This means taking the

time to find out about older people's preferred strategies for managing and looking at ways of helping them continue to use these strategies or adapt them.

2. This research emphasises the importance to older people of informal support from family, friends and neighbours. Many of the older people who took part in the study did not feel comfortable coming forward to seek help from formal services at an early stage, and often found it easier to ask for initial help from family and friends. All this makes current initiatives to support carers and promote community capacity even more important, and it will be important that these are not seen as an easier target for cuts in a difficult financial environment.
3. Older people's preference for receiving support from family and friends can lead them to under-estimate or overlook the need for external involvement. Where relevant, assessments for support should routinely include carer and/or family perspectives so that the level of support available through informal networks and any gaps in this can be reliably established.
4. For many participants – particularly those without access to informal support – having someone to turn to when you needed them was really important. Although the current personalisation agenda may offer additional opportunities to provide this support via new support planning and brokerage roles, this aspect of the health and social care system currently seems under-developed judging by the difficulty older people in this study experienced when trying to navigate their way through services.
5. Local commissioners could make greater use of contracting mechanisms to incentivise home care and social support providers to better meet the needs of older people. Continuity and reliability of support is highly valued by older people, but the reality often falls far short of their expectations. Commissioners might review the extent to which current service specifications, provider selection criteria and contract reviews reflect older people's expectations in relation to continuity of care. Our findings suggest that there is scope to develop these further.

Information and communication

1. Communication is not just about the sharing of information, it is the primary means by which patients can forge meaningful connections, develop trust and feel cared for. Communication training is an established part of medical education, but the focus tends narrowly to be on the skills that professionals need to deliver bad news (104). Further development of education and training is required, so that all of the aspects of communication which can contribute to a positive patient (and carer) experience are recognised and addressed.

2. A consistent finding across all the different groups that participated in this study is that older people want information about their health and local services. Often the information that is required is relatively basic, although needs do vary person to person. Older people themselves are best placed to advise on what information they require, when and in what format. Involving older people in information development would help to improve information quality and provision.
3. While older people want information, they do not always know what questions to ask in order to elicit it. Ultimately, people can find themselves in a situation where they do not know what they do not know. Various tools have been developed to assist patients in accessing information. Question prompts, for example, are lists of questions that patients might wish to ask during a clinical consultation to elicit information about particular needs or issues. Evidence suggests people feel more informed as a result of using questions prompts, without adding additional time to the consultation (105).

10.4 *Summary*

Above all, this study has sought to adopt a participatory approach to our research questions, and arguably the process adopted has been as important as the actual findings. As the health and social care system undergoes radical and rapid change, there is a risk that local areas lose organisational memory and that the focus may be on setting up new structures rather than on improving services for patients. Against this background, our study has tried to identify, train and support groups of older people who can be an ongoing resource to local health and social care communities, acting as a critical friend and using their research skills to explore current changes from a user and carer perspective. Despite barriers and a series of complexities to work through, a participatory approach has had a number of positive benefits and we hope that the experiences and reflections in this report provide useful learning for other researchers, funders and front-line services.

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