Using qualitative research in systematic reviews: Older people’s views of hospital discharge

Systematic reviews have become a cornerstone of evidence-based policy and practice in modern social care. Current practice in systematic reviewing focuses on quantitative studies, yet important additional perspectives can be gained by incorporating qualitative studies.

In this report SCIE uses the example of older people’s views on discharge from hospital to provide a worked example of combining findings from qualitative studies and draws out key messages for systematic reviewing.

This publication is available in an alternative format upon request.
Using qualitative research in systematic reviews: Older people’s views of hospital discharge

Mike Fisher, Hazel Qureshi, Wendy Hardyman and Janet Homewood
Acknowledgements

Summary

1. Systematic reviews and qualitative synthesis

2. Older people and hospital discharge

3. The role of user involvement and the advisory group

4. Search strategy and methods

   4.1 Phase 1: follow-up of review citations
   4.2 Phase 2: systematic searching
      Electronic databases
      Hand searching
      Other searching
      Additional citation tracking and author searching
      The studies identified
      Phase 1 and Phase 2 – inclusion decision
      Results of Phase 1
      Results of Phase 2
      Hand searching
      Other searching
      Additional citation tracking and author searching
      Phase 1 and 2 in summary

5. Assessing study relevance and quality

   5.1 Introduction
   5.2 Criteria for appraisal of relevance and quality
      Decisions about which papers to include in the synthesis
      The 'strong' studies: characteristics, coverage and quality
      Characteristics
      Coverage
      Quality

6. The qualitative synthesis: process and findings

   6.1 Process of synthesis
   6.2 The findings of the synthesis
      Consistent theme of low participation
      Explanations for low levels of participation
Apprehension about discharge
Relationship between control over decision making, anxiety and other factors
Professional perspectives on discharge planning and patient participation
Assessment and life post-discharge
   Older people's perspectives on post-discharge
Discharge to residential care
Summarising and demonstrating the synthesis
The implication of this synthesis for services to older people

7. Methodological conclusions

References

Appendix A: Databases and search strategies
Appendix B: Studies identified through search processes
Appendix C: Data extraction and quality appraisal forms for the 15 studies included in qualitative synthesis
Appendix D: Example text search
Acknowledgements

Our thanks to the advisory group:

Barry Chalkley
Geoff Fawcett
Edith Feasby
Anna Foster
Kathleen Hillaby
Frank Kelly
Joan Machulec
and to Angela Godfrey for recruitment and facilitation, and to an anonymous referee.
Summary

Systematic reviews have become a cornerstone of evidence-based policy and practice in modern welfare democracies. The UK has developed major review centres, such as the Centre for Reviews and Dissemination at the University of York and the Evidence for Policy and Practice Information and Co-ordinating Centre at the Institute of Education, University of London. The Social Care Institute for Excellence (SCIE) is currently developing systematic reviews in social care. The Cochrane and Campbell Collaborations coordinate international work in health and social welfare.

However, current methods of systematic review are focused almost exclusively on how to synthesise effectiveness studies – addressing the question of whether a method of social intervention works. Little work has been developed on synthesising the messages from other kinds of studies that might tell us additionally why interventions do or do not work, and whether they produce outcomes that matter to people who use services.

The term ‘narrative synthesis’ refers to a descriptive account using words rather than numbers to describe the combined effects of different studies. This report produces a descriptive synthesis from qualitative studies, so could be referred to as ‘qualitative narrative synthesis’. We have shortened this cumbersome term to ‘qualitative synthesis’. Because this approach has not been widely used in social care, SCIE decided to develop a worked example of applying qualitative synthesis to a social care topic.

The chosen topic is older people’s views of hospital discharge. This is a policy area in the UK that has been subject to a conventional, high-quality systematic review, but which lacks attention to the views of older people about what they value in terms of both process and outcomes.

The general research question was framed as ‘What are older people’s experiences of hospital discharge, and how are they influenced by staff views and behaviour?’ This question raised a number of related sub-questions: What are older people’s explanations for their level of participation in discharge processes? What are staff views (within the same hospital) about older people’s level of participation and the factors influencing this? What are older people’s experiences and priorities immediately after hospital discharge? What characterises non-medical services or interventions that older people value in assisting them to achieve their aims after discharge?

We defined older people as those aged 60 or over and stipulated that the studies must explore their experience of hospital discharge rather than, for example, that of hospital or community care more generally.

The qualitative synthesis is based on a selective search that identified 104 relevant studies, of which 28 were selected for detailed evaluation and 15 for synthesis. Most studies in the synthesis focused primarily on hospital discharge of those older people without cognitive or communicative impairment, who required some assistance on returning home. Therefore, the synthesis may be of limited relevance to those admitted for minor conditions who return home without the need for assistance, or to people with severe cognitive impairments or communication difficulties who were not interviewed.
The work was guided by an advisory group of older people with experience of hospital discharge, who made important contributions to this study about inclusion criteria, study quality and analytic themes. This approach added the kind of sensitivity to key issues that stems from direct experience; and this influenced the literature searches, the definition of outcomes that were considered important, and the definition of criteria for inclusion and quality appraisal. It also provided an opportunity to test the relevance of key conceptual categories during synthesis.

This report shows that qualitative synthesis of older people's views on hospital discharge is feasible and productive. It helps to explain other review findings about interventions that were found to help older people to deal with being discharged, and, in particular, it highlights the importance of the information and education ingredients in effective interventions and why an intervention that begins prior to discharge from hospital and continues when the older person returns home is more effective. However, it also reveals a significant new dimension – the need to locate the experience of hospital discharge within a life-planning perspective for older people.

This report also notes limitations in the reporting of primary studies of people's experiences and views. If research studies are to be subject to qualitative synthesis, improvements are required in the depth of description and the reporting of socio-demographic detail. Within these limitations, this report offers a detailed example of how qualitative synthesis can enhance systematic reviews in the field of social care.
1. Systematic reviews and qualitative synthesis

The task of the Social Care Institute for Excellence (SCIE) is to create, maintain, disseminate and implement the evidence base for policy and practice in social care. By evidence base, SCIE means the systematically and rigorously collected knowledge available from research, accounts by service users and carers, policy makers and practitioners, and accounts of implementing services.

Systematic reviews provide one of the key foundations for evidence-based policy and practice. Instead of relying on selective studies, systematic reviews base policy and practice recommendations on an exhaustive search for all available evidence. Bias is minimised by assembling as complete as possible a picture of the knowledge available, and by using explicit and rigorous methods of analysis.

However, the development of systematic review methods has been uneven. The major international bodies working on systematic reviews in health and social care (the Cochrane and Campbell Collaborations) have prioritised questions of effectiveness, and have therefore given primary emphasis to methods of examining controlled outcome studies. If other questions also matter, such as why interventions do or do not work or whether they offer the outcomes that people using services want, then different kinds of studies must be examined, and different review methods employed.

The different kinds of studies that are required include qualitative accounts of the views of those receiving services, and descriptive and observational work on how interventions are put into practice (so-called ‘process and implementation studies’). In the systematic review community, these are sometimes referred to as ‘studies with diverse designs’ and since such studies by definition use a variety of methods, they require different kinds of methods to synthesise their findings.

The term ‘narrative synthesis’ refers to a descriptive account; it means using words rather than numbers to describe the combined effects from different studies. The approach can be used in relation to different kinds of studies, and one set of (currently draft) guidelines recommends it as a first step in any synthesis. This report produces a descriptive synthesis from qualitative studies, so could be referred to as ‘qualitative narrative synthesis’. We have shortened this cumbersome term to ‘qualitative synthesis’.

There is now a stream of work on developing systematic reviews to incorporate additional sources of evidence. This work includes the Evidence for Policy and Practice Information (EPPI)-Centre’s innovative approach to synthesising knowledge from different sources, critical accounts of the omission of non-trial sources and worked examples of how the inclusion of process and implementation studies can illuminate the findings of systematic reviews of controlled studies. Some of this work also develops methods of synthesis that are appropriate to different kinds of knowledge sources, particularly findings from qualitative studies.

However, little of this work has been undertaken in social care, and none of the examples cited above directly relates to social services. Accordingly, SCIE has developed a programme of work to fill this gap, including an overview of methods of
synthesising findings from studies with diverse designs and this current report, which is designed to provide a working example of qualitative synthesis in the field of social care, specifically older people’s views of hospital discharge.

While this report contributes to the development of systematic reviews in social care, it should not be treated as a complete systematic review: although every systematic review selects studies for inclusion, this review was based on a limited rather than exhaustive search.

Nevertheless, the intention is that a working example of qualitative synthesis, directly relevant to a key topic in social care, will provide a starting point for systematic reviewers who wish to extend their methods and remit to social care.
2. Older people and hospital discharge

We chose to focus on older people and hospital discharge because of new policy developments and the existence of a high-quality systematic review that was clearly relevant to the topic. While the purpose of the current report is primarily methodological rather than policy evaluation, some policy aspects of the review must be described in order to explain how we selected studies for qualitative synthesis.

Like many developed welfare states, the UK is struggling to find ways of providing welfare that is based on the needs of its citizens, rather than on the services that happen to be available. One key aspect of this is that, for most of the UK, health needs are met through services provided by central government, while social needs are met through services provided by local government. Since health and social needs are closely intertwined, the service distinction poses serious problem for those who use services, and for locally and centrally governed service providers who must sort out financial accountability and service responsibility. The danger is that people will find that responses to their needs are defined by this service split, rather than by what works best to support them.

Nowhere is this more evident than in services to older people, who constitute major users of both health and social services. And nowhere is this problem more acute than in relation to hospital discharge, since health providers argue that their efficiency in discharging older people once their healthcare needs have been met is compromised by the inability of local social services to provide appropriate post-discharge care.

In January 2004, the reimbursement element of the Community Care (Delayed Discharges etc) Act 2003 was implemented, under which scheme local authorities are to make payments to the health authority for each day where a person notified as fit for discharge remains in hospital. Significant new funding (£300 million over two years) was made available to local authorities, suggesting that the primary purpose was to spark the development of appropriate support, rather than simply to penalise local authorities.

There were two kinds of evidence about the potential effectiveness of discharge arrangements – the review by Parker and colleagues showing that support could be successfully provided to older people discharged from hospital, and international evidence from Sweden, where a similar reform had been implemented. Closer examination of this evidence provided some of the key reasons why this qualitative synthesis of older people’s views of hospital discharge was undertaken.

The review by Parker and colleagues shows that the discharge schemes lowered re-admission rates without adverse effects on mortality. However, it contains little conclusive support for any of the particular types of hospital discharge schemes it evaluated. The single most pronounced effect was found for an educational intervention with cardio-vascular patients, and in general, interventions that continued from hospital into the home after discharge had the largest effect. The review found no evidence to support commonly cited remedies to improve discharge (for example, through better multidisciplinary working, or through the nomination of a single point of responsibility for discharge).
This does not mean, of course, that such remedies were found to be ineffective: it means simply that the review did not identify any controlled outcome studies on this issue. As a consequence of this restricted definition of evidence, the authors criticise what they label 'evidence-free' service development, although subsequently the report suggests that greater use of observational data may help to illuminate these and other unexplained issues.\textsuperscript{9} This provides one key avenue of exploration – whether there are other kinds of studies of hospital discharge that would throw light on the value of such remedies.

The review lacks a consistent approach to incorporating the perspectives of older people themselves about what matters in hospital discharge. Although the authors argue that studies "do not demonstrate either that patients or carers are included in the process, or that outcomes related to their well-being, satisfaction or the costs they might incur have been considered in a robust manner",\textsuperscript{9} they do not investigate studies that might report such issues. This is the second key avenue of exploration – whether the existing review of hospital discharge could usefully be enhanced by incorporating studies of older people's views of the outcomes that matter to them.

The international evidence from Sweden also provides some key reasons for looking at older people's views. The Swedish Ädel reform, dating from 1992, gave local authorities substantial resources to expand their residential and care facilities for older people. The resources included some 20 billion SKR as transfers from county councils (who would otherwise have had to provide hospital care), and 3 billion SKR from central government. The evaluation of this reform suggested success in transferring responsibility, but that there was continuing concern about the possible low quality of care provided in the new services and the use of sedation.\textsuperscript{12,13} Since the question of what counts as quality of life post-discharge must include the views of older people themselves, this reinforces the need to consider whether there is valid and reliable evidence about this.

Both sources of evidence, therefore, raise questions about the ingredients of successful support for older people following discharge from hospital and whether systematic reviews that underpin policy and practice take account of what older people might want. In the light of this, we decided to focus this qualitative synthesis on the views of older people about hospital discharge.

The general research question was framed as 'What are older people's experiences of hospital discharge, and how are they influenced by staff views and behaviour?' This question raised a number of related sub-questions: What are older people's explanations for their level of participation in discharge processes? What are staff views (within the same hospital) about older people's level of participation and the factors influencing this? What are older people's experiences and priorities immediately after hospital discharge? What characterises non-medical services or interventions that older people value in assisting them to achieve their aims after discharge?

We defined older people as those aged 60 or over and stipulated that the studies must explore their experience of hospital discharge rather than, for example, that of hospital or community care more generally.
In view of the primacy of older people’s views, we stipulated that reports must derive from face-to-face contact (for example, from an interview, rather than merely from a survey or questionnaire) and we anticipated that structured questionnaires with closed questions would be excluded. As the search progressed, however, the influence of the advisory group changed this last aspect of the definition so that surveys or questionnaires based on previous, more open-ended work, or designed in collaboration with older people were included (see Chapter 4).
3. The role of user involvement and the advisory group

SCIE guidelines for the conduct of systematic reviews call for the involvement of users and carers. It is clear that this has now become a core requirement for research in social work and social care and that users and carers have a key role to play. This may include the entire range of systematic review activities, from specifying the topics for review, through analysis, to writing the report and disseminating its findings. Exactly how and when to involve users and carers, however, is less clear.

For example, user and carer involvement is structurally embedded in SCIE’s governance and working practices: users and carers are members of SCIE’s Board, the Partners’ Council that advises the Board, and the Quality Assurance Board that guides SCIE’s systematic review activity; users and carers participate in awarding and reviewing externally commissioned work; and commissioned work must demonstrate how users and carers will be involved. However, the current study of older people’s views of hospital discharge forms part of SCIE’s development work on systematic reviews and was not separately approved by user and carer members of SCIE’s Boards.

Moreover, the processes of systematic review involve some highly technical tasks (particularly data extraction, quality appraisal and synthesis), and it is questionable whether users and carers would see this as the first call on their time as a way of influencing services. (The exception, of course, is users and carers who themselves are researchers.) This is a question primarily for users and carers to decide, but they may be more inclined to expect those working in the public sector to have the required skills and to use them in accordance with the principles of involvement. Thus the question may be more how to generate proper accountability to users and carers as stakeholders, than to ensure that the time of users and carers is spent in the technical processes of review.

Even taking this view, however, there remains the question of how to incorporate the expertise of people with experience of the services that are the topic of the review. (Again, where a research review is led by users and carers, this issue may not arise.) In the current study, several members of the research team had experience of hospital discharge and of dealing with functional impairment requiring adjustment in the long term, but none was aged 60 or over (our definition of ‘older’ ) and none had had to make such adjustment in the pressured context of hospital discharge.

With these considerations, we decided to establish an advisory group of older people with experience of hospital discharge. The aims were to ensure that older people’s perspectives on what counts as outcomes were included in the review process, and particularly that the research team was sensitised to themes in the studies to be synthesised. Since the emphasis was on the views of older people, we did not set out to include carers (although several members were, or had been, carers as well).

The advisory group of seven older people was recruited from a variety of sources including services provided by Age Concern, and older people attending an Open University course on Health and Social Care. All three men and four women were aged
at least 70 and had experienced hospital discharge within the previous 12 months. The members had very varied experiences of the hospital discharge process, ranging from poor to excellent. Within the group there was experience of being a carer as well as experience of being a patient, and also experience of private and public services. The group met twice, and individual consultations at home were also undertaken with members who could not attend one or other of the two meetings.

The first meeting focused on identifying key areas of importance that researchers should be aware of in the initial searches of literature, and on the older people’s evaluative views about different ways of collecting information. Some initial background information was presented about existing knowledge and understanding of the area to provide a context for the discussion, and to test its credibility with those who had direct experience.

These initial discussions influenced the decisions made about what information to record during data extraction by sensitising the researchers to possibly important features of the discharge experience, as well as likely themes. The group endorsed the researchers’ expectations that organisational context and staff behaviour and attitudes might be important but, in addition, considered that the reasons for hospital admission might to some extent underlie older people’s different experiences. In particular, possible important features of context were whether admission was booked and planned or an emergency; and the nature of the condition which led to admission, particularly the degree to which the condition and its treatment varied in their impact upon individuals, thus making the development of a routine process more difficult for some conditions than others. Group members were conscious of the influence of wider factors, such as shortages of beds, on the process of discharge. Some scepticism was expressed about the willingness of staff to take advice from older people, and there was recognition that some older people needed encouragement to question staff, and to persist if they were not satisfied with the answers. This reinforced expectations that information, and how, or whether, it was exchanged, would be an important theme to explore. The respect with which older people were treated also emerged as an issue.

On methods, group members expressed the view that open questioning gave people a better opportunity to express their views in their own way. Some members were strongly in favour of group-based methods. (In the event, however, we did not find any studies that had used group methods with older people who had specifically experienced hospital discharge.) In addition, older people felt that it would be an advantage (or, in systematic review terms, a ‘possible indicator of quality’) if studies collected views from older people after discharge as well as before.

As will be evident from the completed data extraction forms (Appendix C at: www.scie.org.uk/publications/reports/report09c.pdf), these discussions influenced the methodological and contextual information recorded about each study during the data extraction process.

At the second meeting the results of the synthesis were presented to the group. The older people largely supported the findings, as presented, but again emphasised that individual experiences varied widely and urged the importance of distinguishing between admissions for major as opposed to minor conditions or treatments. The
advisory group welcomed the emphasis given in the results to those services or experiences that had been positively evaluated by older people. The advisory group highlighted the views of older carers facing decisions about residential care as an important additional perspective that was not covered in our selected studies. Concern was expressed at the long-term persistence of problems in discharge processes and the apparent failure of many attempts to address these, despite the existence of good practice demonstrating that success was possible.

Group members received a summary of the final report and the full report if they wished. All members were paid a fee for their participation, as well as expenses.

We would not, of course, claim that this was the ideal example of user involvement in systematic reviews: for example, older people were not involved in selecting the topic for study. However, the account demonstrates that a general commitment to user involvement can be applied to systematic reviews: it adds the kind of sensitivity to key issues that stems from direct experience, and this influences the way searches for literature are conducted, and what outcomes are considered important; it contributes to the definition of criteria for inclusion and for quality appraisal; and it provides an opportunity to test the relevance of key conceptual categories during synthesis.
4. Search strategy and methods

The search underpinning this working example was not intended to be the kind of exhaustive process that is designed to ensure that systematic reviews draw on all available evidence. Nevertheless, the concepts of 'transparency' (explicit and rigorous methods) and 'replicability' (the extent to which others can reproduce the results) require reviewers to show their sources and working methods, so this chapter reports the search processes in detail. This chapter uses the term 'reference' (that is, a study of potential relevance) and 'record' (that is, a potentially relevant entry retrieved from electronic database searches) interchangeably in order to ensure the language is familiar to both researchers and to information scientists.

The searching was undertaken in two phases. Phase 1 was a follow-up of references cited in the original systematic review by Parker and colleagues, and Phase 2 involved a search of electronic databases, journal hand searching, and citation tracking. The purpose of these two phases was to locate as many references as possible, so that they could then be subject to a decision about inclusion or exclusion.

Review teams should also consider another key method of locating studies. Arai and her colleagues report a process of contacting the authors of the primary studies used in systematic reviews to discover whether the studies generated any information on the processes or implementation of the intervention that were not reported in the review, or were reported elsewhere. In the field they were investigating (the effectiveness of smoke alarms in preventing child accidents), studies were examined and this revealed significant new information, but was extremely time consuming. We decided that the timetable for the current review did not permit scope to use this method (there were 54 studies in the review by Parker and colleagues). An alternative – to use author citation tracking to locate material that might amplify the primary study – would locate material more readily if it was published. This option did not occur to us until after the search was complete.

Returning to the current study, the broad criteria for inclusion were that studies:

- concerned older people (aged 60+)
- concerned their experience of hospital discharge
- were based on older people’s experiences and views directly, sought through face-to-face contact (rather than through a postal survey or questionnaire).

Alongside these processes, the consultation with the advisory group during the search phase drew attention to the need to consider studies that collected data before as well as after discharge, so that some account could be taken of the variety of issues older people were facing. The group also confirmed the importance of searching for studies that directly reported older people’s views.

4.1 Phase 1: follow-up of review citations

The Health Technology Assessment (HTA) by Parker and colleagues reported the results of a systematic review of discharge arrangements for older people. The findings of the review were based entirely on synthesis of findings from 54 randomised controlled
trials (RCTs), and did not include any qualitative research. In their introduction, however, the authors highlighted several papers concerning the views and experiences of older people and their carers. These specific papers were retrieved and assessed for potential inclusion by three members of the project team (MF/WH/HQ).

In addition, each member of the project team scanned the main reference section of the HTA report individually, in order to identify any other potentially relevant references, and then discussed their proposals for retrieval with the whole team. On the basis of these discussions, additional references were then retrieved.

The combination of searching for references using the methods above resulted in the retrieval of a limited number of papers. These results are reported in Chapter 5 in the report. Additional searching was therefore undertaken, which is reported in Phase 2.

4.2 Phase 2: systematic searching

This phase of the search process used several methods to identify additional literature:

- electronic database searches
- hand searching electronic contents pages of two key journals
- other searching – papers identified in a non-systematic way by team members
- additional citation tracking and author searching – from papers deemed potentially relevant and tracking references and author names from papers.

4.2.1 Electronic databases

Bibliographic databases covering social work, social sciences and health literature were searched during the period 19-28 April 2004. Details of which databases were searched are provided in Table 1.

The search was initially conducted for papers published over a five-year period from 1999-2004 for all of the databases listed. This was extended to 1995-2004 for those databases anticipated to contain greater numbers of relevant social care records (CareData, AgeInfo, PsycInfo, Social Sciences Citation Index). No language limits were applied. Details of search terms used are provided in Appendix A.

Table 1: Databases searched

<table>
<thead>
<tr>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>AgeInfo</td>
</tr>
<tr>
<td>CareData</td>
</tr>
<tr>
<td>CINAHL (Cumulative Index to Nursing and Allied Health Literature)</td>
</tr>
<tr>
<td>MEDLINE</td>
</tr>
<tr>
<td>PsycInfo</td>
</tr>
<tr>
<td>SIGLE: System for Information on Grey Literature in Europe</td>
</tr>
<tr>
<td>Social Sciences Citation Index</td>
</tr>
</tbody>
</table>
The use of precise keywording was not always productive and led to few studies being found. The information scientist (JH) therefore also browsed all records that had relevant general keywords and used free text searches on the above databases.

An additional search was also conducted on AgeInfo and CareData using the terms 'intermediate care' and 'intermediate care' and 'older people' as key words or in the title or abstract of papers.

The results from each search were entered into an electronic reference library program (EndNote) and duplicate records removed. The information scientist conducting the search scanned the results of the database searches and identified records of potential relevance to the review. Given that the search of many of the databases resulted in very large numbers of irrelevant ‘hits’ this acted as an initial filtering phase. The first 20 records identified from CareData acted as a guide to this process, and was informed by team discussions regarding which records were not relevant.

4.2.2 Hand searching

Electronic journal contents pages (title and abstract where available) of the journals *Ageing and Society* and *Age and Ageing* were searched for the period 1999-2004. Table 2 reports the volumes and issues accessed.

Two members of the project team each read all of the contents pages for the issues noted and identified potentially relevant records on the basis of titles and/or abstracts (depending on whether they were available). They compared their results and discussed any differences in their selections. Full papers were then requested for records that both team members agreed were potentially relevant.

### Table 2: Hand searched electronic journals

<table>
<thead>
<tr>
<th>Journal</th>
<th>Volume, Issue, Year searched online</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Ageing and Society</em></td>
<td>24 (1-4) 2004</td>
</tr>
<tr>
<td></td>
<td>23 (1-6) 2003</td>
</tr>
<tr>
<td></td>
<td>22 (1-6) 2002</td>
</tr>
<tr>
<td></td>
<td>21 (1-6) 2001</td>
</tr>
<tr>
<td></td>
<td>20 (1-6) 2000</td>
</tr>
<tr>
<td></td>
<td>19 (1-6) 1999</td>
</tr>
<tr>
<td><em>Age and Ageing</em></td>
<td>33 (1-4) 2004</td>
</tr>
<tr>
<td></td>
<td>32 (1-6) 2003</td>
</tr>
<tr>
<td></td>
<td>31 (1-6) 2002</td>
</tr>
<tr>
<td></td>
<td>30 (1-6) 2001</td>
</tr>
<tr>
<td></td>
<td>29 (1-6) 2000</td>
</tr>
<tr>
<td></td>
<td>28 (1-6) 1999</td>
</tr>
</tbody>
</table>

Note: *Additional supplements were also searched.*
4.2.3 Other searching

Papers were also identified in a non-systematic way by project team members, using their knowledge of the field.

4.2.4 Additional citation tracking and author searching

Additional records were also identified through tracking reference sections of some of the papers and reports identified in Phase 1 and Phase 2. This process was limited, as the volume of material retrieved may have been too great for the project team to handle; essentially a judgement was made about the relevance of a citation or about whether an author was undertaking a programme of relevant work.

4.3 The studies identified

The full list of 104 studies is given as Appendix B. The references are listed in the author-date format (for example, Age Concern, 2002).

4.4 Phase 1 and Phase 2 – inclusion decisions

All papers/reports identified as potentially relevant from Phases 1 and 2 of the review were retrieved and read by at least two (MF/WH) and usually by three (MF/WH/HQ) members of the project team. All papers were assessed for potential inclusion within the project against the original criteria, but refined through discussion with the advisory group of older people as follows:

- Studies must report the views of older people, obtained through direct interviews, either using open methods or using structured questions on issues that older people have designated as important. (Examples of the latter: studies where there was direct involvement of older people in the design of the questions; studies reporting an explicit basis for questions in prior open-ended work with older people; or studies addressing issues highlighted as important by our advisory group of older people.)
- Studies must clearly concern people with experience of discharge (not older people who might have views on discharge), and we must be able to attribute findings or quotes specifically to respondents who offered views about discharge.

Studies that met such criteria were put forward for in-depth analysis and potential synthesis.

4.4.1 Results of Phase 1

This led to an initial identification of 18 records: six records from those highlighted by authors of the Parker et al review and 12 from additional scanning of the reference section. Thirteen of these records were excluded after reading the full report/paper. Five papers were identified as relevant for Phase 3 (Harding and Modell, 1989; Jewell, 1993; McWilliam and Sangster, 1994; Tierney et al, 1994; McBride, 1995).
4.4.2 Results of Phase 2

A total of 58 records were retrieved from the database searches (See Table 3).


4.4.3 Hand searching

This revealed a limited number of papers discussing patients’ experiences of hospital discharge. There were many general commentaries on intermediate care but very few reported older people’s experiences of being discharged from hospital.

This strategy led to the identification of eight articles (five from Ageing and Society, three from Age and Ageing). Only one of these papers was deemed relevant for inclusion in detailed analysis (Cunliffe et al, 2004).

4.4.4 Other searching

This led to the identification of two records, only one of which was deemed relevant for inclusion in detailed analysis (Huby et al, 2004).

4.4.5 Additional citation tracking and author searching

This led to the identification of 18 records, six of which were deemed as relevant for detailed analysis (Coulton et al, 1989, Jewell, 1996, Jones et al, 1989, Congdon, 1990, Bull and Kane, 1996, Clare and Hofmeyr, 1998).

Table 3: Search results from electronic databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Potentially relevant 'hits'</th>
</tr>
</thead>
<tbody>
<tr>
<td>AgeInfo</td>
<td>11 (10 from main searches, 1 using 'intermediate care' search term)</td>
</tr>
<tr>
<td>CareData</td>
<td>9 (0 additional records using 'intermediate care' search)</td>
</tr>
<tr>
<td>CINAHL</td>
<td>1</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>4</td>
</tr>
<tr>
<td>PsycInfo</td>
<td>15</td>
</tr>
<tr>
<td>SIGLE</td>
<td>7</td>
</tr>
<tr>
<td>Social Sciences Citation Index</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total relevant 'hits'</strong></td>
<td><strong>58</strong></td>
</tr>
</tbody>
</table>
Searching on author names did not lead to the identification of any further papers, other than those already known about.

**4.4.6 Phase 1 and 2 in summary**

Through these methods, a total of 104 records was initially identified as of potential relevance to the project. A further 76 of these were excluded at a later stage, leaving 28 for inclusion in detailed analysis.

Table 4 provides a detailed breakdown of the number of potentially relevant records from Phases 1 and 2 of the search and those finally included in detailed analysis.

Systematic reviews require reviewers to be transparent about the decisions to include or exclude studies and Table 5 summarises the decisions made on the 76 excluded studies.

In some cases, it was clear from either the title or abstract that the work did not include the views of older people. Where there was doubt, the paper was retrieved and read. In the case of two reports in Dutch, however, where a rough translation of the abstract did not fully resolve relevance, we decided that the four-figure translation cost could not be justified for this project.

**Table 4: Sources of potentially relevant records and final inclusions**

<table>
<thead>
<tr>
<th>Source</th>
<th>Potentially relevant</th>
<th>Excluded</th>
<th>Included in detailed analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parker et al, (2002) ⁸ 48:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>references highlighted by authors</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Identified from reference section</td>
<td>12</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td><strong>Phase 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic databases:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AgeInfo</td>
<td>11</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>CareData</td>
<td>9</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>CINAHL</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>PsycInfo</td>
<td>15</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>SIGLE</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Social Sciences Citation Index</td>
<td>11</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Hand searching electronic journals:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age and Ageing</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Ageing and Society</td>
<td>5</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Additional citation tracking</td>
<td>18</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Other searching</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>104</td>
<td>76</td>
<td>28</td>
</tr>
</tbody>
</table>
The majority of decisions to exclude a paper were made after it had been read in full. This is not as daunting as it sounds; often the title or abstract misleadingly implied relevance, and a quick scan identified the absence of relevant material. The process does, however, make the reviewer pray for adherence to the scientific convention of including a section clearly labelled ‘methodology’ in reports of studies. All too often the necessary information was buried in the detail, as though it were a minor matter to be reported in passing. In three cases, material could not be retrieved in the required timescale, and in one case a report that appeared to be a separate study, summarised, in fact, a study for which the full report had already been obtained.

Accounts of inclusion and exclusion decisions in a systematic review impose a neat sense of order on often quite messy processes, involving compromise and disagreement on judgements. The decision to exclude material because it could not be retrieved in time, for example, depended on a shifting assessment of how quickly material could be obtained, tracking authors to sometimes distant parts of the globe, and hoping that what we were holding out for would prove important enough to warrant the wait. In other words, it is a judgement call about when to call a halt to tracking down material.

In the current study, seven papers arrived or were identified too late for inclusion, and these are detailed in Box 1. Note that there is no implication that these studies would have been included in the detailed analysis.

Reviewers should also note where there is disagreement about inclusion. In the current study, there were nine papers about which the three research members of the team disagreed (Clare and Hofmeyer, 1998, \textsuperscript{43} Closs et al, 1995, \textsuperscript{21} Cornes and Clough, 2001, \textsuperscript{44} Jones and Lester, 1994, \textsuperscript{45} Jones et al, 1989, \textsuperscript{40} McBride, 1995, \textsuperscript{19} Rastall and Davies, 1997, \textsuperscript{46} Reed et al, 2002, \textsuperscript{47} Victor and Vetter, 1988). \textsuperscript{48} After discussion, four papers were included in the detailed analysis (Clare and Hofmeyer, 1998, \textsuperscript{13} Closs et al, 1995, \textsuperscript{21} Jones et al, 1989, \textsuperscript{40} McBride, 1995). \textsuperscript{19}

### Table 5: Excluded records

<table>
<thead>
<tr>
<th>Reason for exclusion</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial read of abstract/title</td>
<td>13</td>
</tr>
<tr>
<td>Reading of full paper/report</td>
<td>57</td>
</tr>
<tr>
<td>In foreign language (Dutch) and too costly to translate</td>
<td>2</td>
</tr>
<tr>
<td>Unable to retrieve from microfiche</td>
<td>1</td>
</tr>
<tr>
<td>Unable to retrieve</td>
<td>2</td>
</tr>
<tr>
<td>Summary of full report already retrieved</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total excluded</strong></td>
<td><strong>76</strong></td>
</tr>
</tbody>
</table>

The majority of decisions to exclude a paper were made after it had been read in full. This is not as daunting as it sounds; often the title or abstract misleadingly implied relevance, and a quick scan identified the absence of relevant material. The process does, however, make the reviewer pray for adherence to the scientific convention of including a section clearly labelled ‘methodology’ in reports of studies. All too often the necessary information was buried in the detail, as though it were a minor matter to be reported in passing. In three cases, material could not be retrieved in the required timescale, and in one case a report that appeared to be a separate study, summarised, in fact, a study for which the full report had already been obtained.

Accounts of inclusion and exclusion decisions in a systematic review impose a neat sense of order on often quite messy processes, involving compromise and disagreement on judgements. The decision to exclude material because it could not be retrieved in time, for example, depended on a shifting assessment of how quickly material could be obtained, tracking authors to sometimes distant parts of the globe, and hoping that what we were holding out for would prove important enough to warrant the wait. In other words, it is a judgement call about when to call a halt to tracking down material.

In the current study, seven papers arrived or were identified too late for inclusion, and these are detailed in Box 1. Note that there is no implication that these studies would have been included in the detailed analysis.
Although (as in every systematic review) the inclusion criteria guide these decisions, there are some very fine judgements. For example, some excluded studies (Cornes and Clough, 2001, Rastall and Davies, 1997, Reed et al, 2002) contained interesting material on discharge, but on a full reading it proved impossible to tell whether the older people had experience of the event. Similarly, although Victor and Vetter (1988) obtained older people's views, the postal questionnaire was designed without the input of older people.

The above discussion outlines the kinds of search processes and decisions that underpinned the decision to include in the detailed analysis phase of the project a total of 28 studies out of the 104 initially identified.
5. Assessing study relevance and quality

5.1 Introduction

This chapter focuses on decisions made about which papers to include in the synthesis, and the nature and quality of the studies included.

The 28 papers selected all had some degree of focus on hospital discharge and older people. The next step was to read these papers, to make a judgement about their relevance and quality in more depth, and to extract the data that we would need for qualitative synthesis.

When a large number of potentially relevant articles has been identified, the process of quality appraisal in systematic reviews is often separated from data extraction, with data on findings being extracted only from papers that pass a quality threshold. However, the number of papers under consideration in this instance was relatively small, so we decided to extract data for synthesis and for making quality judgements at the same time, in one process. The intention was to concentrate the subsequent synthesis on the data extracted from the studies we judged as ‘strong’, leaving the option, if time permitted, to re-examine the data from the ‘weak’ papers for any insights into older people’s views, which might be useful for corroborating, strengthening or refuting the synthesis. Whether or not to include a paper in the synthesis is a judgement that combines several different aspects of relevance and technical quality. It is likely, therefore, that the quality of those papers included will vary. After decisions had been agreed about which papers to include, those selected were subject to a more detailed quality appraisal, covering a number of dimensions that will be detailed in this chapter.

The purposes of data extraction were thus fourfold:

- To record information from each paper in a consistent format in order to make a judgement about potential inclusion or exclusion in synthesis, based on the likely relevance of the evidence to our questions; and, for those potentially included, to record an assessment of the capacity of the study to make a strong or weak contribution to synthesis.
- To record information on the design and methods used in each study, as a basis for the more detailed appraisal of the relative quality of studies included in the synthesis. As will be outlined, these appraisals were based on the study design, the centrality of older people’s views, the depth of reporting and analysis, and generalisability.
- To record consistently features of context, if reported, that might affect older people’s experiences, such as the reasons for admission to hospital, type of ward, staff attitudes, behaviour or views, and the organisation and integration of health and social care services.
- To identify and record older people’s perspectives on hospital discharge as reflected in each paper, in a consistent format to aid synthesis of emerging themes.

Two researchers (MF, HQ) independently undertook data extraction on the 28 papers. One function of this exercise was to familiarise both researchers with the data, but it also enabled researchers to compare data that had been extracted in relation to
themes, concepts and the context that was to be used for synthesis, and this process of comparison will be discussed in Chapter 6. (In order to allow the reader access to the categories used and our judgements, the completed data extraction forms for the 15 studies included in the synthesis are available in Appendix C (www.scie.org.uk/publications/reports/report09c.pdf).

5.2 Criteria for appraisal of relevance and quality

When it comes to the selection of criteria for appraisal we may be spoilt for choice: Dixon-Woods et al identified over 100 sets of criteria; and a report from the Cabinet Office, attempting to rationalise the large range of criteria available, identified a ‘mere’ 28. Our own process of defining the criteria for quality appraisal illustrates the complexity of doing this work and the need to be reflective and explicit.

5.2.1 Decisions about which papers to include in the synthesis

Prior reading of the papers and discussion of the literature on qualitative synthesis had generated a sense of what would constitute ‘strong’ and ‘weak’ relevance to the aims. After some discussion, part way through the process of data extraction the following explicit definitions were agreed:

• Strong: at least one primary focus is on the views of older people in relation to the process of hospital discharge, or their experiences immediately pre- or post-discharge which might have been affected by that process and methods that have been used which privilege the subjective views of older people, that is, open-ended methods or occasionally less open-ended methods explicitly based on prior work with older people using open-ended methods and reporting that provides ‘thick’ or detailed description or, in the case of quantitative work, investigation of relationships between concepts, not just frequency counts.

• Weak: at least one primary focus is on the views of older people in relation to the process of hospital discharge, or their experiences immediately pre- or post-discharge which might have been affected by that process but reporting is thin on description or largely limited to basic frequency counts, so that only one or two possible insights into the nature of older people’s subjective views have been generated.

• Exclude: the focus of the study or its methods or the (lack of) depth of analysis mean that it does not yield data on the subjective views of older people in relation to hospital discharge or it yields data restricted to a particular time and place without any information or analysis that would enable inferences to be made to other possible contexts.

It is important to stress that studies judged as ‘weak’ were so in relation to our question. In relation to other questions that did not privilege the subjective views and meanings expressed by older people, the quality of these same studies may well be judged differently. We did not intend that this marker of the subjective views and meanings expressed by older people should necessarily rule out quantitative approaches, but there had to be some evidence that the views of older people had influenced the structure of data collection. Authenticity of this kind might, for example, be achievable through previous qualitative data collection, or through the active involvement of older people in deciding which structured questions to pursue.
Box 2 below contains the 28 studies included in the data extraction phase.

**Box 2: 28 references included in the data extraction phase***


Note: * 15 studies subsequently rated 'strong'.

After data extraction from the 28 papers, the two researchers agreed on 15 papers as 'strong'. In a small minority of instances, consideration of the data led to uncertainty about which papers to select. Uncertainties were resolved through discussion and agreement (see Box 3 below for examples of such issues).

**Box 3: Examples of issues arising at different stages of selection**

1. Initial screening: exclusions

This paper focused on hospital discharge and used a new methodology which was unfamiliar, but of some interest, to the reviewers. A strength of the paper was its involvement of older people as co-researchers with professionals. However, it was not clear whether the older people had any experience of hospital discharge, nor was there any information about the numbers or characteristics of older people involved. Finally, in the reporting it was not possible to separate the user voice, and, given our aim to focus on the voices of older people, this paper was therefore excluded.

2. Quality and relevance appraisal: selected for appraisal but excluded from synthesis (‘weak’)


This paper was a largely quantitative satisfaction survey, although some limited qualitative data was reported. There was some analysis by different hospitals but no information given about the characteristics of the hospitals in the report. Variations might have been interpretable in the specific local context, but not by readers of the report with no knowledge of the context. This lack of contextual information limited generalisability. However, the paper was one of the few which contained any specific information about older people from minority ethnic groups. The paper did not generate data which could be included in the synthesis but might add to analysis post-synthesis through corroboration or refutation of findings, or by providing a way to link in material about older people from minority ethnic groups.

3. Quality and relevance appraisal: included in synthesis (‘strong’)


These studies focused primarily on the post-discharge experience. Both were qualitative studies, to which older people's views were central, although the study by Clark et al was larger and generated a greater wealth of data. Information about discharge itself was quite limited in both cases. However, given the advice from the advisory group of older people about the importance of data collected after discharge, and the potential implications of these study respondents' experiences for the discharge process, it was decided to include these papers in the synthesis.

### 5.3 The 'strong' studies: characteristics, coverage and quality

#### 5.3.1 Characteristics

Of the 15 studies, nine were from the UK, three from the US, two from Canada and one from Sweden. Dates published were 1989, 1990, 1993, 1994 (3), 1996 (3), 1999 (2), 2002 (2), 2004 (2). Table 6 below gives a brief overview of the 15 studies rated as strong.
### Table 6: Overview of ‘strong’ studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Date</th>
<th>Place of study</th>
<th>Older people</th>
<th>Design</th>
<th>Method</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main author</strong></td>
<td></td>
<td></td>
<td>Number and how selected</td>
<td>Key to abbreviations: B – before; A – after; x2 – at two time points</td>
<td>Note: Interviews are face to face unless otherwise specified</td>
<td></td>
</tr>
<tr>
<td>Bull and Kane</td>
<td>1996</td>
<td>USA</td>
<td>25 admitted for acute episode of chronic condition eg diabetes</td>
<td>B&amp;A. Ax2 1.2 weeks after 2.2 months after</td>
<td>Interview – 25-90 minutes semi-structured</td>
<td>Yes</td>
</tr>
<tr>
<td>Clark et al 23</td>
<td>1996</td>
<td>UK (England)</td>
<td>30 prospective study 20 retrospective study People who received equipment or adaptations from occupational therapy service</td>
<td>30 B&amp;A Ax2 1.1 month after 2.3 months after</td>
<td>Interview – approx 1 hour. Accounts of experience rather than direct questioning. Observation</td>
<td>Yes</td>
</tr>
<tr>
<td>Congdon 41</td>
<td>1990</td>
<td>USA</td>
<td>8 people discharged from 4 acute wards Stated theoretical sampling but no details in this paper</td>
<td>Unclear (either B or A) (one interview between day before discharge and two days after – distribution not given)</td>
<td>Interview Ethnographic interview lasting 45 minutes. Observation.</td>
<td>Yes</td>
</tr>
<tr>
<td>Coulton et al 37</td>
<td>1989</td>
<td>USA</td>
<td>264 people who required post-hospital long-term care (30 days plus)</td>
<td>B&amp;A A – 30 days post-discharge</td>
<td>Interview. Data in this paper relies on items with a fixed response format</td>
<td>No</td>
</tr>
<tr>
<td>Cunliffe et al 35</td>
<td>2004</td>
<td>UK (England)</td>
<td>20 12 chosen to reflect experimental or control groups by levels of frailty. Then a further 8 on the basis of emerging findings</td>
<td>B&amp;A Ax2 1.4 weeks 2.3 months Complementary study to a large RCT</td>
<td>Interview with interview guide. Plus open comments from structured questionnaires in the main RCT.</td>
<td>Yes</td>
</tr>
<tr>
<td>Author</td>
<td>Date</td>
<td>Place of study</td>
<td>Older people</td>
<td>Design</td>
<td>Method</td>
<td>Staff</td>
</tr>
<tr>
<td>---------------</td>
<td>------</td>
<td>----------------</td>
<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Espejo et al</td>
<td>1999</td>
<td>UK (England)</td>
<td>32 Those discharged to residential care only Referred by nurses.</td>
<td>B only</td>
<td>Interview – semi-structured 20 minutes to 1 hour. Plus test battery for statistical comparison with those discharged home</td>
<td>No</td>
</tr>
<tr>
<td>Huby et al</td>
<td>2004</td>
<td>UK (Scotland)</td>
<td>22 Purposive sampling to reflect age, gender, condition and type of ward (stroke or medical or geriatric rehab)</td>
<td>11 B only 11 B&amp;A A – minimum of 2 weeks</td>
<td>Interview – semi-structured observation</td>
<td>Yes</td>
</tr>
<tr>
<td>Jewell</td>
<td>1993</td>
<td>UK (England)</td>
<td>5 Each chosen to reflect one of five typical case scenarios constructed from study of records</td>
<td>A only 10-14 days</td>
<td>Interview – semi-structured 30 minutes to 4 hours</td>
<td>Yes</td>
</tr>
<tr>
<td>Jewell</td>
<td>1996</td>
<td>UK (England)</td>
<td>5 Rehab unit</td>
<td>B only (Bx3) 1. 48 hours post-admission 2. on choice of destination 3. 24 hours before discharge</td>
<td>Interview – taped Described as qualitative analysis using ethnograph</td>
<td>No</td>
</tr>
<tr>
<td>Krevers et al</td>
<td>2002</td>
<td>Sweden</td>
<td>14 Selected by nursing staff as capable of being interviewed. Not random.</td>
<td>5 B only 9 B&amp;A 'some weeks after'</td>
<td>Interview – semi-structured 1 hour</td>
<td>No</td>
</tr>
<tr>
<td>Author</td>
<td>Date</td>
<td>Place of study</td>
<td>Older people</td>
<td>Number and how selected</td>
<td>Data available</td>
<td>Method</td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
<td>----------------</td>
<td>--------------</td>
<td>-------------------------</td>
<td>---------------</td>
<td>--------</td>
</tr>
<tr>
<td>LeClerc et al.</td>
<td>2002</td>
<td>Canada</td>
<td>Older people</td>
<td>Admitted for acute illness. Selected from an acute hospital and a community care centre.</td>
<td>No</td>
<td>In-depth interview – semi-structured. 1-1.5 hours.</td>
</tr>
<tr>
<td>McWilliam and Sangster</td>
<td>1994</td>
<td>Canada</td>
<td>Older people</td>
<td>Selected to compare rural (12) and urban (9) contexts</td>
<td>Yes</td>
<td>Interview – conversational style with topic guide</td>
</tr>
<tr>
<td>Powell et al</td>
<td>1994</td>
<td>UK (England)</td>
<td>Older people</td>
<td>All those discharged in a given period from a short-stay rehab ward</td>
<td>Yes</td>
<td>Interviews – loosely structured case notes</td>
</tr>
<tr>
<td>Reed and Morgan</td>
<td>1999</td>
<td>UK (England)</td>
<td>Older people</td>
<td>Discharged to residential care from acute/rehab geriatric wards</td>
<td>Yes</td>
<td>Telephone interview (A1 and A2)</td>
</tr>
<tr>
<td>Tierney et al</td>
<td>1994</td>
<td>UK (Scotland)</td>
<td>Older people</td>
<td>All aged 75+ admitted for 48+ hours from home (and going back)</td>
<td>Yes</td>
<td>Interview (B1 and B2)</td>
</tr>
</tbody>
</table>

Key to abbreviations: B – before; A – after; x2 – at two time points

Note: Interviews are face-to-face unless otherwise specified.
All the studies collected some information through face-to-face interviews with older people. The interviews were variously described as semi-structured, loosely structured or conversational. The one exception in terms of structure of data collected was provided by Coulton (1989). This paper was based only on the responses to structured, closed questions. It was included because it addressed issues that the advisory group had indicated were important (for example, control of decision making and anxiety about discharge). In addition, its relatively strong theoretical basis allowed analysis of the relationships between concepts that other papers had indicated were relevant but had not analysed. Despite this being the earliest of the published studies, no subsequent studies built on its arguments, suggesting that researchers in this field could improve their work by conducting systematic literature searches before research is undertaken.

5.3.2 Coverage

Two studies were primarily concerned with post-discharge experiences rather than the discharge process itself. Two further studies focused exclusively on older people who were not returning home but were being discharged into residential care. Although some other studies also included a number of older people entering residential care, not all made it clear whether people who were not returning home were included. Most studies focused primarily on the hospital discharge of older people who required some assistance on returning home. This focus is understandable in that this is the group most likely to be disadvantaged by poor discharge planning. At the same time, most 'strong' studies excluded people with severe cognitive impairments or communication difficulties, such that an interview would be unlikely to generate reliable data. While these exclusions are understandable, given the methodology of the studies, and also apply to many of the studies in the review by Parker et al, people with severe cognitive impairment or communication difficulties are a significant group that requires careful discharge planning. Therefore, findings from the synthesis of the included studies cannot be assumed to apply to people with severe cognitive impairments or communication difficulties, nor to those admitted for minor conditions who return home without the need for assistance.

5.3.3 Quality

Although all of the papers passed our threshold for inclusion in the synthesis, there was nevertheless some variation in the quality of the studies. In appraising the relative quality of the studies, we decided to use four markers relating to: strength of design, centrality of older people's views, quality of analysis and reporting, and generalisability. These four markers indicate the extent to which each of the included studies:

- gave material most relevant to our question (strength of design)
- gave a central position to the views of older people (centrality of older people's views)
- were reported in enough depth and detail to give confidence in the findings (quality of analysis and reporting)
- gave information that would permit some generalisation beyond the immediate context in which the data were collected (generalisability).
In making these kinds of quality judgements, many issues of interpretation must be tackled. Here we detail some of the major issues that underlie the judgements.

In judging strength of design, we were asking how appropriate the design was for answering the questions posed in the study. With the help of the advisory group, we decided that two aspects that contributed to strength of design were: first, the inclusion of data collection before and after discharge; and, second, a face-to-face method of data collection with instrumentation designed to generate a set of data primarily shaped by older people’s concerns, rather than those of professionals or of organisations.

The criterion of centrality of older people’s views derives from the fact that we wanted to discover older people’s own views and concepts, expressed in their own words, in accounts structured as they wished. This was judged in terms of the way the study reported its aims and methods, in terms of any reference to participative methods or methods of building trust and rapport with older people, and in terms of whether the study built on previously reported studies of older people’s views.

In making this a marker of study quality, we were building on other attempts to use qualitative studies in systematic synthesis. Harden et al’s examination of systematic reviews on children’s health, for example, commented that, despite using a number of quality criteria, one important omission related to the relevance of primary studies to the review question. Thus, in their case, an important consideration was whether the studies reflected young people’s views. Similarly, Noyes et al considered that the privileging of subjective experience and meanings would be one mark of study quality, given their aim to uncover a particular kind of knowledge: patients’ motivations for following a given treatment regime.

At the same time we sought to judge quality in the analysis and reporting. This is sometimes referred to as distinguishing ‘thicker’ description. We thought that studies had greater analytic power if they:

• used cross-checking between analysts
• investigated the relationships between concepts as well as giving simple description (although theory building or testing per se was relatively rare, and this was not used to judge quality)
• supported interpretations with direct quotations of what older people said, and
• clearly indicated the source of such reported views.

Where quantitative data was also reported, we judged that studies had greater strength if they went beyond reporting simple frequencies to investigate the relationships between factors and if they related those investigations to concepts that older people (and/or our advisory group) had identified as important.

In terms of generalisability, we sought to judge the quality of information on the selection and composition of the sample, the degree to which the achieved sample reflected that which the study design intended, and the description of contextual factors that might have influenced the findings.

Table 7 shows the agreed judgements made in relation to the 15 studies.
Table 7: Quality appraisal of ‘strong’ studies

<table>
<thead>
<tr>
<th>First author</th>
<th>Design</th>
<th>Centrality</th>
<th>Analysis and reporting</th>
<th>Generalisability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bull and Kane (^{42})</td>
<td>Good B&amp;(AxA2) Explicit grounded theory approach</td>
<td>Good Yes. Same interviewer on each occasion Semi-structured interviews</td>
<td>Acceptable/good Paper reported on two studies – sometimes difficult to disentangle source of data for results Some thick description on communication. Only one quote from an older person</td>
<td>Acceptable no gender breakdown Age range and mean Exclusions not specified All with chronic health conditions</td>
</tr>
<tr>
<td>Clark et al(^{23})</td>
<td>Good B&amp;(AxA2) Plus (study 2) A only</td>
<td>Good Clear focus on older peoples’ views and experiences Open methods</td>
<td>Good Policy and practice orientation, not much link to theory</td>
<td>Acceptable/weak numbers only no demographics; all recipients of OT services</td>
</tr>
<tr>
<td>Congdon(^{41})</td>
<td>Weak/acceptable Unclear info on timing of interviews Some A only, some B only</td>
<td>Good Relevant focus on older peoples’ experiences and open methods</td>
<td>Weak Reporting limited</td>
<td>Acceptable Total 8 only. Age range only, no gender info Alleged theoretical sampling no info. from acute wards</td>
</tr>
<tr>
<td>Coulton et al(^{37})</td>
<td>Acceptable B&amp;A Interviews but these results based on closed questions from interviews</td>
<td>Weak No reported exploration of older peoples’ definitions But is based on previous more open-ended studies. Reflects issues advisory group deemed important</td>
<td>Good Tests based in clear theoretical framework Quantitative</td>
<td>Good People needing post-hospital care Demographics, exclusions given</td>
</tr>
<tr>
<td>First author</td>
<td>Design</td>
<td>Centrality</td>
<td>Analysis and reporting</td>
<td>Generalisability</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>Cunliffe et al 35</td>
<td>Good B&amp;(Ax2)</td>
<td>Good Focus on older people's views, open methods</td>
<td>Good/acceptable Elements of thick description</td>
<td>Good Criteria for purposive sampling detailed No gender breakdown</td>
</tr>
<tr>
<td></td>
<td>In-depth interviews</td>
<td>Open methods (in context where primary aim was to explain RCT results)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explicit link to RCT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Espejo et al 28</td>
<td>Acceptable B only plus statistical comparison with group going home</td>
<td>Acceptable Focus on residential care makes it important because this group often excluded</td>
<td>Acceptable Limited reporting though categorisation of attitudes is developed</td>
<td>Good Age/sex breakdown given Exclusions specified. Non-random nature of sample acknowledged</td>
</tr>
<tr>
<td></td>
<td>Open methods but not taped</td>
<td>Sensitivity not discussed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Huby et al 36</td>
<td>Good B&amp;A (11)</td>
<td>Good OP views central Supplemented interviews with conversations to explore significant events</td>
<td>Good Thick description, OP views as reference point for other data, life history perspective</td>
<td>Good Criteria for purposive sampling specified. Age and sex given</td>
</tr>
<tr>
<td></td>
<td>B only (11)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Observation informal conversations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jewell 36</td>
<td>Acceptable A only</td>
<td>Good Focus on older people's views in particular context/scenario</td>
<td>Good Latent analysis for each case scenario</td>
<td>Acceptable Number very small (5) but selection for typicality enhances generalisability</td>
</tr>
<tr>
<td></td>
<td>But selected to reflect 'typical' case scenarios</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jewell 39</td>
<td>Acceptable Bx3</td>
<td>Good Focus on older people and participation</td>
<td>Acceptable Detailed data on experiences in hospital. Methods of analysis not reported</td>
<td>Acceptable Small numbers (5/7) respondents from lists awaiting admission to rehab unit. Demographics, exclusions given</td>
</tr>
<tr>
<td>First author</td>
<td>Design</td>
<td>Centrality</td>
<td>Analysis and reporting</td>
<td>Generalisability</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------------------</td>
<td>------------------------------------------------</td>
<td>-------------------------------------------------------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>Krevers et al</td>
<td>Good B&amp;A 9 B only 5 Open methods</td>
<td>Good Focus on OP perspectives</td>
<td>Good Grounded theory. Some thick description</td>
<td>Acceptable/weak Selection by ward nurses Small numbers Gives demographics</td>
</tr>
<tr>
<td>LeClerc et al</td>
<td>Acceptable A only Depth interviews</td>
<td>Good Prioritises older women’s perspectives</td>
<td>Good Ethnograph grounded theory team of 4 independent coding</td>
<td>Acceptable Women only Post-admission for acute illness &gt;50 % refusals</td>
</tr>
<tr>
<td>McWilliam and Sangster</td>
<td>Good/acceptable 15 at least x2 in 10 days post-discharge Semi structured interviews records and observation</td>
<td>Acceptable OP central starting point Chain sampling of professionals and carers from older person. But reporting more about context than OP perspectives per se</td>
<td>Good Details of analysis and cross checking. Some thick description</td>
<td>Good ‘Maximum variation sampling’ (by diagnosis) Those with continuing care needs Age/gender given</td>
</tr>
<tr>
<td>Powell et al</td>
<td>Good/acceptable A only Open methods</td>
<td>Good OP perceptions central</td>
<td>Good Few details of method Thick description in reporting</td>
<td>Good Demographics and exclusions given All discharged from rehab ward for OP</td>
</tr>
<tr>
<td>First author</td>
<td>Design</td>
<td>Centrality</td>
<td>Analysis and reporting</td>
<td>Generalisability</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Reed and Morgan³⁹</td>
<td>Good/acceptable A only (in care home)</td>
<td>Good Focus on older people’s experiences</td>
<td>Good/acceptable Little detail of analysis</td>
<td>Good</td>
</tr>
<tr>
<td></td>
<td>Open methods</td>
<td>Entering residential care</td>
<td>Thick description</td>
<td>All discharged (to care homes) from 3 wards for OP</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>About half excluded for cognitive impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No demographics</td>
</tr>
<tr>
<td>Tiemey et al¹⁸</td>
<td>Acceptable B(x2)&amp;A(x2) but A mostly</td>
<td>Acceptable/weak Centred on older people</td>
<td>Acceptable Analysis by SPSS</td>
<td>Acceptable/good</td>
</tr>
<tr>
<td></td>
<td>telephone interviews. Closed methods</td>
<td>(and carers) but structured questioning</td>
<td>Some reporting of responses to what appear to be open questions, eg some felt they 'did not have the right to express views'</td>
<td>Not clear about numbers interviewed face to face. 1/5 of those living within the city boundary?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>reflecting pre-defined issues</td>
<td></td>
<td>Gives demographics for the interview study as a whole</td>
</tr>
</tbody>
</table>

Notes:

**Design:** best incorporates before and after (B&A). A only is better than B only. Open methods better than structured questioning. Face-to-face interviews better than telephone interviews.

**Sensitivity, centrality of older people’s views:** best is when there is a specific aim to discover older people’s views in their own words by collecting accounts structured as they wish to structure them. Revealed in aims, methods, participation in research, building on (and building in) older people’s previously reported views, and measures taken to build trust and rapport.

**Analysis and reporting:** best is provided by clearly described methods of qualitative analysis, use of recording, cross checking with more than one analyst, thick description (especially using quotes), deriving categories or relating concepts, focus on older people’s views and clear indication of source of reported views. For quantitative data, analysis that goes beyond simple frequencies and relates to concepts that older people have identified as important in other literature (and/or the advisory group).

**Generalisability:** quality of information on selection and composition of sample. Extent to which results are located in the wider literature. Degree to which achieved sample reflects that which the design intended.

OP = Older People.
One study\textsuperscript{11} was included in the set of ‘strong’ studies despite having a relatively weak design. The judgement here involves a balance of factors: the paper reports data collection methods that clearly prioritise the views of older people, but fails to specify how many interviews were conducted before and after discharge (and implies that no respondents were interviewed both before and after discharge). The study by Tierney et al\textsuperscript{18} was difficult to evaluate until further accounts, referenced in the original, were read; for example, a description that some interviews took place ‘within 24 hours of discharge’ was found to mean 24 hours before discharge, and the interviews after discharge were found to be highly structured, with 65 questions.

The judgements about generalisability should be assessed in the context that reporting of socio-demographic data was usually poor, and (in the 15 studies included in synthesis) never included data on ethnicity.

This chapter has described the processes of judging the quality of the studies and how 15 passed the threshold for inclusion in systematic synthesis. The next chapter describes the type of synthesis undertaken and the findings.
6. The qualitative synthesis: process and findings

6.1 Process of synthesis

Synthesis was conducted using the information from data extraction forms that related to themes, perspectives and context. Occasional reference was made back to the original papers, if needed, for clarification. An initial exercise was undertaken to check the consistency of the data extracted by the two independent researchers (MF, HQ). For this purpose, one researcher (HQ) explicitly compared the themes extracted from the 15 ‘strong’ studies, on a paper-by-paper basis. There were no disagreements about the major findings of the studies, but the sections on the data extraction forms about emerging themes completed by MF contained a larger number of speculative questions, and tentative higher order constructions than those completed by HQ, which were closer to the words and formulations used in the original papers. Extractions by HQ also contained more details of methodology. The level of detail in reporting older people’s views in many of the studies was disappointing from the point of view of providing possibilities for subsequent synthesis. The limited data available may provide one explanation for the high levels of agreement about the extraction of themes.

In order to use computer-assisted qualitative analysis, all text on context and themes was copied from the data extraction forms into a set of text files. These files were analysed with the aid of a simple text analysis programme that provided facilities for coding and retrieving segments of data indexed by their code and their origin. To make full use of insights from both researchers, additional material, or reworked themes, from MF’s data extraction were written to a text file and included in the analysis of the material on themes and contexts extracted by HQ.

The approach to analysis was essentially ‘interpretive’ as described by Dixon-Woods and colleagues, rather than ‘integrative’. Integrative approaches seek to pool similar types of data to enhance their reliability and they require the quantification of qualitative data. We thought that it was unlikely that the experiences and views of older people could be treated in this way, particularly as it was expected there would be a wide variety of types of data reported and little consistency in reporting conventions (this was confirmed during the data extraction phase). It seemed more likely that an ‘interpretive’ approach that identifies related concepts in the primary studies, and tests their consistency, would correspond to the data contained in the primary studies.

This analytic approach was particularly informed by an understanding of the interpretive methods of grounded theory and by the techniques of meta-ethnography, an interpretive synthesis approach employed by a number of researchers in social welfare, grounded theory may provide a common reference point for qualitative synthesis because of its familiarity to the research community and because some of its techniques resemble those used in meta-ethnography. For example, a technique such as reciprocal translational analysis, where similarities are sought between analytic concepts arising in different studies, resembles the method of constant comparison used in grounded theory. Similarly, a technique known as refutational synthesis, where contradictions between studies are sought in order to test the robustness of an
emerging finding from synthesis, is very close to the technique of deviant case analysis used in grounded theory and in other qualitative analysis approaches.\textsuperscript{57}

However, no reviewer approaches synthesis without having been sensitised to some of the dominant themes of interest through question-setting, data extraction and quality appraisal. Completion and comparison of the data extraction forms, and discussions with older people, had generated some expectations about prominent themes that then influenced the broad initial coding categories (codes) applied to relevant segments of the text files. Participation in the discharge-planning process was one such issue. Synthesis thus started by applying this a priori code, wherever relevant, throughout all the text files arising from the data extraction. After one pass through all the text files applying this coding category, the codes were reviewed.

After the first pass through the data it was clear that older people’s lack of participation in discharge planning – often attributed to ‘passivity’ on the part of older people – was a consistent theme. All 15 studies contained at least one statement indicating that lack of participation was the usual state of affairs. In relation to this theme, reciprocal translation across studies presented few difficulties as the accounts were similar and used similar language. Thus we observed that lack of participation applied across a range of healthcare systems (UK, Canada, USA, Sweden). However, a disadvantage of this consistency was that inter-study comparison was unlikely to generate explanations for variations in participation. Although some of the studies referred to findings from others, there seemed to be no discernible development of lines of argument over time. We decided, therefore, to look more closely at this central concept of participation.

One technique for doing this in grounded theory is axial coding, developed by Strauss to refer to the process of “building up a dense texture of relationships [between categories around the axis of a category … by laying out the properties of the category, varying conditions in which it occurs”\textsuperscript{53}

The text files were coded for a second time to develop axial coding around the central category of participation: identifying all instances in which any active participation was reported and all explanations given by participants, either for the rare examples of participation, or for the general lack of it. Following this work, it was clear that the explanations for active participation and passivity reinforced rather than contradicted each other.

Examples of other broad themes identified on the first pass through the text files were:

- From the older people’s perspective: older people’s identification of their problems, fears or anxieties before discharge home; experiences and ways of coping post-discharge; services or experiences positively evaluated by older people; views of staff and interactions with staff, particularly in relation to information exchange; concerns of those facing admission to residential care.
- From the contextual information: staff views of the nature and purpose of the discharge process; staff views of their own role in it; staff views of older people; organisational factors influencing staff behaviour and the discharge process.
Files containing selected (coded) material reflecting the above themes were then extracted from the original text files, reviewed and further coded to indicate sub-categories. For example, the problems and anxieties that older people reported were further classified; and explanations by older people for their active participation, or lack of it, were subsequently grouped into those which related to their perceptions of staff and their behaviour, and those which reflected older people's explanations of their own behaviour. These sets of explanations could then be compared with the explanations and perceptions of staff (where these had been collected).

The output files provided a basis for writing up the findings, together with links back to the individual studies providing the particular pieces of evidence. As each subdivision progressed, it was found that fewer studies were providing the evidence sought, either because studies had not reported in that level of detail, or the participants had not been asked the relevant questions. Sometimes, the fact that the description of concepts lacked depth made reciprocal translation problematic. If studies reported difficulties relating to 'communication' or 'information' for example, but gave no further detail, it was difficult to know whether the meanings of these words would be unpicked in the same way across different studies. Sometimes the phrase 'communication difficulties' referred to inter-professional communication rather than patient-professional communication. Occasionally there was no further elaboration.

The processes of reciprocal translation and refutational synthesis were thus hampered by the fact that accounts from different studies were not so much contradictory as incomplete. Gaps or lack of depth in one study could sometimes be filled by inference from the results of another. It may be questioned whether the findings of one study can be added to, or assumed to be the same as, those of another, if the second study is silent on the subject. For example, if older people in one study give a particular set of reasons for why they do not seek to participate actively in discharge planning, it is possible that people in another study, who have not been asked their reasons, may have entirely different thoughts on the matter. However, the report of the first study is, and remains, the only evidence we have about what people say about the cause of a particular behaviour in a particular context. If people give different reasons in different studies, they may not be contradictory, but of course it cannot be known for certain whether or not the same reasons did apply in both but were not uncovered in one or other study.

In order to clarify the source and limits of evidence in writing up the findings, therefore, each statement in the following findings section is linked by the citation of references to all of the studies from which it was derived. In contrast to a qualitative synthesis that is not based on a systematic selection of studies containing primary evidence, the account of the findings can be read with an assurance that each reference is based on primary data that evidences the point being made. In addition, the data extracted by both researchers from the 15 studies included in the synthesis can be inspected (Appendix C).
6.2 The findings of the synthesis

6.2.1 Consistent theme of low participation

Across the board, the studies reveal a low level of participation in planning for discharge. Researchers in all (15 ‘strong’) studies comment on the passivity of many older people in relation to discharge planning, and their apparent willingness to accept arrangements made by others (see Appendix D at www.scie.org.uk/publications/reports/report09d.pdf). A few older people were reportedly unhappy about their lack of participation \[41,35,18\] and there were active exceptions in the sense that a few did insist on contributing to decision making. Descriptions of those who did make their views known include comments such as “only the articulate, vocal and determined were able to take part with any confidence” \[16\] and refer to people as “active, optimistic, confident and strong willed”, \[32\] suggesting that personal characteristics were seen as influential.

The picture of low levels of participation, and few expressions of discontent with this situation, is consistent across studies. Powell et al (1994) \[20\] observed that “patients and carers valued opportunities to discuss expectations, plans and likely problems with health and social care professionals”. Why then is participation so consistently low? Older people have offered a number of explanations. These relate to their own behaviour, beliefs and motivations, and to the behaviour of staff and the nature of the hospital environment.

6.2.2 Explanations for low levels of participation

Perceived differences in power and status are one issue. The staff – particularly doctors – are seen to be in charge. Older people deferred to professionals; \[17\] they accepted a subservient role, \[39\] and saw discharge as something that professionals control. \[23\] Doctors and nurses “told them what had been arranged” for their discharge. \[42\] Tierney et al (1994) \[18\] found that older people felt that it was not their right to express views. People might feel they had useful information to offer, and ideas about their own illness or discharge targets, but even then they would wait for staff to initiate discussion. \[39,32\]

At the same time, people may not be at their strongest or most assertive when ill. Older people explained their lack of participation as a consequence of the fact that they felt weak, tired, old, resigned \[32\] or were aware of decline in their mental and physical powers. \[36\] In some cases they were reluctant to appear to criticise or complain, or to trouble frontline staff who appeared to be under pressure, \[32,36\] or who had to work according to “their system”. \[33\] Some older people were aware of pressure on beds \[36\] and in one study were told directly by nurses that they had to move on to make room for others. \[29\]

Features of hospital organisation, atmosphere and staff behaviour can reinforce passivity. Tierney et al (1994) \[18\] found that the formality of ward rounds and number of people present inhibited older people from making their views known. Other studies found that staff used language and ways of communicating that older people are not always comfortable with, perhaps because of their sometimes lower levels of education, or because staff use jargon. \[36,33\] Older people in one study \[42\] said that they relied on better educated relatives to negotiate with staff from a more equal position, while
older people in another study saw themselves as having reduced social standing. In relation to professional jargon, Clark et al (1996) argued that assessment did not deal with enhancing independence in the way that older people defined it, and Huby et al (2004) observed that the widespread use of standardised assessment tools inhibited communication because they did not afford older people the opportunity to put any results into context for staff.

Some deference is based on the belief that staff alone have the expertise to know when older people are well enough to manage outside hospital. In this way professional power is legitimated. People trust their doctors to know if they are not ready for discharge, and may not feel they have (or have been given) the information or knowledge necessary to make such a judgement. Much importance is attached by older people and their relatives to any words from a doctor. In this context it is easy to see why conflicting advice from professionals is so unsettling, because it undermines trust in professional expertise, and perhaps therefore increases anxiety. Huby et al (2004) discuss the theme of trust, arguing that while older patients do trust doctors’ clinical expertise, staff also need to trust patients and their competence; but, in their study, this was made more difficult by the dominance of formal assessments in judging competence, and patients’ apparent lack of engagement with the system of discharge planning – a system which was not clear to the older people themselves.

Thus professional power and patient deference are seen to rest on a number of differences in:

• formal hierarchy
• medical expertise
• experience of ‘the system’ in hospital
• levels of health and energy
• education, social standing and the use of language.

The last of the above factors may not impact equally on all patients, and might lead to a hypothesis that patients who have higher levels of education or higher social status may be more likely to participate actively in discharge plans, or at least to express dissatisfaction at their failure to do so. However, few studies recorded such background information about older people. One exception is Bull and Kane (1996) in which a small minority of patients complained of disrespectful attitudes from staff, and it was reported that these patients were more likely to have received education beyond high school.

Formal structured assessments of people’s capacity, whatever their other merits, may inhibit the exchange of information between older people and staff, particularly with respect to information about the older people’s knowledge of the particular individual features of their life at home that may affect both what they need to do, and what they will be able to do.
6.3 Apprehension about discharge

Despite their lack of participation in discharge planning, people in the studies certainly experienced anxieties about their impending discharge, whether or not these were expressed to hospital staff. Cunliffe et al (2004) reported that nearly all the older people in their study expressed apprehension about their discharge. One factor which might suppress the expression of such apprehension is that people do actually want to get out of hospital: it is a sign of recovery, a step towards resuming normal life. For some, there may even be anxiety and uncertainty about whether they will be "allowed home". In so far as more general apprehension or anxiety is unpicked in the studies, it encompasses the following: safety, particularly fear of falling, how they will manage or cope and being a burden to others, although Congdon (1990) says that most were relatively insensitive to sacrifices made by relatives, concern that they are not really well enough, being able to recognise anything abnormal once discharged, losses and what may have to be given up, depending on the 'illness trajectory' and level of disability. Coulton et al (1989) found that those with lower ADL scores (Activities of Daily Living, a questionnaire measuring help required, in which lower scores mean higher levels of impairment) experienced higher levels of anxiety about discharge.

We interpret these areas of anxiety as reflecting people’s perceptions of threats to their safety and self-sufficiency after discharge.

6.4 Relationships between control over decision making, anxiety and other factors

The study by Coulton et al (1989) was unusual in that it employed a strong theoretical basis (‘locus of control theory’) to explore relationships between anxiety about discharge decision making, people’s expectations and beliefs about their own control of events, actual control of the decision, and outcomes such as satisfaction and psychological well-being. Coulton et al found that people with low expectations of their own control over events experienced less anxiety about decisions relating to hospital discharge. Perhaps they were more content to place themselves in the hands of others (Coulton et al do not speculate). However, those who expected to be able to control events but then did not do so, experienced reduced psychological well-being, compared with those who had no such expectations. This study therefore suggested that people’s initial disposition to expect control over decisions might influence their levels of anxiety about discharge decisions and their reactions to lack of control. However, given that those older people who had control over decisions made about their discharge from hospital experienced increased satisfaction after discharge, irrespective of whether such control was expected or not, this study suggests that meaningful participation, if carefully handled with respect for individual differences, is likely to have benefits in terms of subsequent patient satisfaction.

In a small-scale Swedish study, Krevers et al (2002) made the most detailed qualitative categorisation of older people’s attitudes and behaviours in relation to participation in the discharge process, identifying four self-defined groups of older people, labelled: ‘active’, ‘frustrated’, ‘tolerant’ and ‘passive’. They suggested a connection to the concept of illness trajectory, with those who were most active having illness of recent onset.
and anticipating a full recovery. Those who were described as frustrated also faced relatively recent illness but with a deteriorating or uncertain future and their attempts to participate were frustrated by feelings that they lacked knowledge and expertise, as well as by a strong sense of illness. People in the ‘tolerant’ group were more accepting of their lack of participation, more content for staff to be in control, in the short term at least, sometimes ascribing this tolerance to their personality. In general, they too expected to recover, although this might take some time. These three groups were contrasted with those who were ‘passive’, who faced longer-term deteriorating health or an uncertain future, and had ceded control to staff or relatives. Thick description in this study illustrates the ways in which personality, history, illness trajectory, length of illness, and professional behaviour all interact to influence the extent to which older people can or do participate in discharge planning. Unlike Coulton et al., who see ‘locus of control’ as a relatively stable feature of personality, Krevers et al. report that older people saw themselves as having changed expectations of control, as a consequence of their experiences, illness or history.

We interpret both of these studies as indicating the importance of older people’s perceptions, experiences and expectations of their degree of control over events. They suggest that expectations influence the degree to which a lack of control will, in the event, impact negatively on psychological well-being. However, Krevers et al., although a small-scale study, explore a wider range of possible factors that affect the extent to which people are content to cede control and suggests that, while personality may be a factor in creating expectations, the length and seriousness of illness, and the direction of the illness trajectory are also influential. In the light of our understanding of pre-discharge anxieties, the concept of trajectory complicates the ‘threat’ posed to self-sufficiency, suggesting that for some older people anxiety in this regard may be lessened by the expectation of full recovery. For others, who are already experiencing long-term illness and facing possible deterioration, the prospect of engaging in future reciprocity is reduced, and ceding control to trusted others may be a response to this situation, either because it reduces anxiety, or because there is perceived to be no other choice. Our interpretation is that the frustration experienced by those newly facing illness with a deteriorating or uncertain future is related to the difficulty of determining the degree of threat faced and the consequent difficulties in planning ahead. Older people do not have the information that will permit them to exercise control, nor do they trust others at this stage to exercise it for them. In contrast, many of those anticipating an eventual full recovery may tolerate ceding control to others in the short term (and in the hospital context with its deference-inducing features), in the expectation of being able to resume control later.

6.5 Professional perspectives on discharge planning and patient participation

Staff were conscious that discharge is subject to other pressures unrelated to patient readiness, such as variable pressures on beds, in particular. Such pressures were seen to vary by rural/urban location, by type of ward, surgical more than medical, with more time available for dealing with discharge issues in specialist geriatric or rehabilitation settings, or settings with a dedicated discharge team.
When they were asked, staff usually expressed the view that they believed patients were involved in discharge planning, or that the level of participation was determined by patient willingness. In some settings it was not always clear which member of staff was responsible for initiating such discussions and it was accepted that physical care of patients on the ward would take priority over discussion about issues related to hospital discharge at busy times. Reed and Morgan (1999) discuss the perceptions of different staff about their own expertise and their responsibilities; for example, it was not seen as the role of nurses or doctors to discuss issues with older people who were moving to residential care, unless perhaps nurses had a role to 'cheer them up' if they expressed anxieties. But it was the role of the doctor to decide on discharge. The role of social workers was to respond quickly to demands/pressure to discharge, leaving them with limited time to see the person; indeed it was found that an older person could be discharged to residential care without seeing the social worker who was making the arrangements.

The general findings of those studies that included health service staff seem, therefore, to suggest that they are largely unaware of older people’s perspectives on why they do not participate.

6.6 Assessment and life post-discharge

Staff priorities at discharge were seen by researchers to be centred on safety, and risk management. The drivers of assessment were variously described as:

- meeting physical and safety needs at discharge, and plans matched to existing services
- functional capacity and safety and
- risk minimisation.

From an extensive study of older people’s lives post-discharge, Clark et al (1996) argue that “The conceptual framework of professional assessment does not incorporate individual's responses to impairment or how they respond to threats to the boundaries of their independence. These adjustments take time, thought, reflection by the older person and renegotiation of boundaries. But the primary focus of assessment at discharge is safety”.

Thus, a further difference between staff in hospital and their older patients is a difference of focus in relation to discharge. With the exception of the specific discharge scheme in Cunliffe et al (2004), staff were found to be focused on safety and the management of risk in the short term, and saw the discharge date as the end of their involvement. In contrast, we shall show that older people, although also concerned about safety and short-term risk, have a primary focus on the longer term, dealing psychologically and practically with their changed and changing health state, with living their life and maintaining their autonomy, and the discharge date, and attendant immediate risks, is seen as only a beginning.
6.6.1 Older people’s perspectives on post-discharge

Clark et al (1996)\(^{23}\) indicated that coming to terms with change (for example, decreased mobility or physical capacities, needing assistance from others) could be a more important issue for older people than safety per se. It was also emphasised that coming to terms was not a passive process of acceptance but working out how to manage, how to preserve control over the most important things while accepting what must be given up. Issues of professional power were evident in the descriptions of the ways in which some older people concealed their chosen ways of coping from professionals (and also relatives) because they feared that they might have been considered too risky.

After discharge, people often experienced some improvement in their condition\(^{35}\) and this recovery, and regained abilities to manage, could generate new confidence.\(^{23}\) However, recovery could be at a slower rate than they had hoped.\(^{32,42,33}\) People continued to experience restricted mobility and weakness or fatigue, as well as chronic symptoms such as pain,\(^{35,42,33}\) and might worry about the extent to which this was normal or to be expected. A study of women after acute illness\(^ {33}\) found that “No one in the hospital had prepared them for how slow the recovery process would be”. Another study reported that “active patients were becoming disappointed, beginning to define their trajectory as more uncertain”.\(^ {32}\) Sometimes unanticipated symptoms materialised, such as fatigue.\(^ {35}\) In some studies, it was found that older people and informal caregivers received various inadequate information on being discharged from hospital or during their hospital stay, about their medication, treatment, dietary needs or the likely progress and management of their condition.\(^ {16,17,42}\) Patients are now asked questions on these issues in the regular NHS in-patient surveys, so it seems that their importance is recognised. However, passive provision of information, whether written or verbal, may not be enough. For example, older people in Powell et al’s study\(^ {20}\) particularly valued active teaching about medication that they received while in hospital, and practice in using it.

For those older people who were troubled by uncertainties or lack of information, ready access to professional staff who they knew and who knew about their history was much appreciated\(^ {17}\) and its absence was experienced as a problem.\(^ {23}\) People reported that they were uncertain about which professional to ask about what when they needed to cope with changes,\(^ {17}\) or that they were reluctant to trouble physicians for information if it seemed to query their expertise.\(^ {35}\)

Cunliffe et al (2004)\(^ {35}\) explicitly compared the experiences of people who had received services from a specialist discharge team with those who had not, and found that older people valued the reliability and availability of team members, and were particularly appreciative of frequent visits for care and rehabilitation soon after discharge. Such contact, as well as being of practical assistance, could help to allay uncertainties and doubts about progress, or the emergence of new symptoms or side-effects. It should be noted that, in the study by Cunliffe and colleagues, the older people appreciated care more than rehabilitation, and expressed a preference for slow-stream in-patient rehabilitation settings over (some of the) general medical settings.
Uncertainty is the fundamental factor in problems experienced by older people in the short term after discharge. Uncertainties experienced by older people about their health relate to the expected rate of progress, persistence of symptoms (or appearance of new ones), and the side-effects of drugs. People may also be uncertain about what they need to do to help themselves to recover. We hypothesise that interventions mentioned in these studies such as the provision of information, and patient training and education, serve to reduce uncertainties, thus giving older people confidence both in their self-reliance and in seeking further advice from health professionals, if required, about their prognosis and symptoms. In the same way, a service that provides continuity of staff between hospital and home gives immediate access to information, reassurance and appropriate action from known professionals, should these uncertainties arise.

In the longer term the process of actively coming to terms with change will predominate. Impairment and ill health, especially if they are lasting, impose a need for a re-evaluation of how to manage one’s life. Re-evaluation requires time for both reflection and actual experience of the home environment and the new health status. Data from Clark et al (1996), in particular, detail the elements of this process of deciding what is important, preserving control over the important things and re-establishing a preferred lifestyle. At this stage some level of risk may well be accepted in order to preserve control over an individual’s life choices.

Our interpretation of all of the findings is that it is this longer-term life-planning focus that underpins people’s needs for information and support in the context of change and uncertainty before, during and after hospital discharge.

Of course, quality of life post-discharge is much affected by the quality of community-based services, but this report has focused on issues linked to hospital discharge, as that is the question our review sought to address. Discharge from hospital to residential care presents a special case and evidence about this is given below.

### 6.7 Discharge to residential care

Those about to enter residential care from hospital are more likely than others to be involved in discussion of their options, and people who wish to resist going into residential care may actively insist on their say. However, in general, this particular group may not feel they have full ownership of the decisions taken and may have limited opportunities for discussion with health professionals or social workers. When residential care is being considered as an option, the home visit is sometimes described as an arena in which conflicting perspectives about the possibility of returning home are played out.

It was found that older people did not see themselves as having many choices or control over care decisions in this context. In Espejo’s et al study (1999), a minority of older people felt it was definitely their own choice to enter a residential service, and a minority were completely opposed to going, but, where reported, the majority of people had mixed feelings: a varying mixture of acceptance, fear and anxieties, with an underlying theme of loss of people, home and possessions and independence.
Reasons people have given for entering residential care are: safety and the need to be looked after, poor mobility, being unable to walk, in particular, poor eyesight, loneliness and the desire to avoid being a burden to others. People variously hoped to be looked after, to be safe, to find company, to be able to do more, and to be relieved from anxiety and uncertainty. Before entering residential care older people reported a range of fears and anxieties including:

- loss of control over their life
- adjusting to communal living
- not getting on with other residents
- boredom and being cut off from life
- poor hygiene in homes
- financial costs
- general uncertainty and worry as to how things would be.

Some service responses addressed lack of choice, and fears and anxieties. In Powell et al’s study (1994) older people were able to visit a range of homes before deciding, and those people who were able to discuss issues with a social worker all found this reassuring. However, Reed and Morgan (1999) reported that the time spent by social workers on making arrangements for placements meant that they might not even see the older person concerned at all. It was reported that nurses, even if they had sufficient time, did not feel equipped to discuss the prospect of entering a home with older people because they did not know about homes, or felt negative about them. They would allegedly attempt to “cheer up” people who were going into care if they seemed to need this but, as one put it, they did not like to disturb a situation where someone had “accepted their fate”. Medical staff did not regard such discussion as part of their remit.

People about to enter residential care are facing a future in which threats to their personal safety will be reduced, but they are apprehensive that their control over their life will also be reduced. These studies show that older people faced a range of uncertainties about social life in the homes, care regimes, and their own adjustment to communal living. Interventions reported as being valued by older people, such as discussion with a social worker, and visits to prospective homes, may then assist by reducing uncertainty and offering information about the nature of life in homes, which may reassure people about aspects of control that can be retained and planned for.

6.8 Summarising and demonstrating the synthesis

Qualitative synthesis is more than a rigorous literature review: it should reach beyond the findings and research interpretations in the studies to demonstrate how the synthesis generates “a greater degree of insight and conceptual development than is likely to be achieved in a narrative literature review”. Similarly, Britten et al (2002) suggest that synthesis represents “a conceptual development that constitutes a fresh contribution to the literature.”

The draft guidance on narrative synthesis by Popay et al 2004 suggests a number of ways of showing this process, including ‘idea webbing’, conceptual mapping, conceptual triangulation and tabular presentations. The example by Britten et al (2002) showed such a table with three columns, designed to make clear the differences between:
• everyday understandings and meanings as reported to researchers in the studies
• second-order constructs of social scientists (both concepts and relationships) as drawn from the papers being synthesised, and
• finally, that which Britten et al label third-order interpretations, which combine second-order concepts and relationships to produce explanations and hypotheses which, in some respects, go beyond those in the original studies. 58

The relationships between the third-order explanations and hypotheses are then linked in a line of argument that seeks to provide a coherent account of the field of study addressed by the synthesis.

Because our synthesis had undertaken similar translation processes, it seemed to us that this approach of tabulating the synthesis would work best to show the processes at work. Table 8 summarises the lines of argument and the concepts developed in the synthesis.
Table 8: Summary of synthesis, including second and third-order interpretations

<table>
<thead>
<tr>
<th>Concepts/themes</th>
<th>Second-order concepts and relationships</th>
<th>Third-order interpretations/hypotheses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explanations for low levels of participation (a common theme in all studies)</td>
<td>Power, status and deference</td>
<td>Patients with higher educational levels and social standing may be slightly more likely to insist on participation in discharge planning. Past experience in hospital may enhance confidence to participate.</td>
</tr>
<tr>
<td>Positional power (doctors and nurses are in charge of patients)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Power from experience (doctors and nurses understand the system)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standing/education/class (doctors and nurses are better educated and have superior social standing)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reluctance to criticise (staff perceived as under pressure and doing their best)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expertise (doctors and nurses know best about health and illness)</td>
<td>Trust (reduces anxiety) Dependency (for treatment and information)</td>
<td>Trust is undermined (and therefore anxiety increases) if experts do not agree. Anxiety increases when access to medical expertise is reduced. Expertise legitimates power.</td>
</tr>
<tr>
<td>Disagreement among experts a problem for patients</td>
<td>Capacity for assertiveness undermined Physical dependency.</td>
<td></td>
</tr>
<tr>
<td>Impact of illness (older people feel weak, tired, in pain)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expectations of recovery</td>
<td>Trajectory</td>
<td>Expected direction of trajectory influences expectations of the degree to which self-sufficiency, and previous lifestyle, will be recovered (see anxieties). (Personal resources may influence the extent to which this is perceived as a threat to autonomy)</td>
</tr>
<tr>
<td>• Expecting recovery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Deteriorating health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Uncertain</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Classification from Krevers et al.\(^2\) only

Those most passive in the discharge process face longer-term deteriorating health or an uncertain future and have ceded control to others.

Those who expect to recover fully are either active (particularly if illness is recent), or tolerant about ceding control to staff but see it as short term.

Those with recent illness with uncertain or deteriorating future felt frustrated in attempts to participate by lack of knowledge and expertise.

### Anxieties (pre-discharge)

- Will they be ‘allowed’ home (for some)
- Fear of falling
- How they will manage or cope
- Being a burden to others
- What will have to be given up

- Those entering residential care cite these anxieties as reasons, combined with sense of loss

The act of discharge means a sign of recovery, a step towards resuming normal life.

### Second-order concepts and relationships

- Combination of time since onset and expected trajectory influence degree of active participation in discharge planning and willingness to cede control to others.
- Anxiety less where people have low expectations of control (quantitative data)
- If people have higher expectations of control but these are not realised then this impacts on their well-being (psychological) (Quantitative data)

### Third-order interpretations/hypotheses

- Long-term dependency and lack of opportunities for reciprocity is an anxiety provoking prospect. Ceding control to others if faced with this is: anxiety reducing?
- Something that people come to terms with over time (because they have no choice?)?
- At least some people who do not participate in hospital but expect to recover (eventually) are just ‘biding their time’, expecting to be able to take back control of their life in future?
- Lack of the information needed to plan your future in the face of change is frustrating

Anxieties:

- Threats:
  - to future safety and self-sufficiency
  - to future autonomy
  - to lifestyle choices

- Cause anxiety
- Anxiety is associated with higher levels of impairment (quantitative)
- Those entering residential care expect to be safe but fear loss of autonomy and lifestyle choices

Higher levels of anxiety associated with higher levels of impairment, and a deteriorating or uncertain trajectory, because of these threats

In particular expected trajectory indicates likelihood of being able to engage in present or future reciprocity and therefore increases or decreases the threat posed to self-sufficiency.

Resuming normal/previous life is an aspiration/aim
### Concepts/themes

<table>
<thead>
<tr>
<th>Post-discharge experience</th>
<th>Second-order concepts and relationships</th>
<th>Third-order interpretations/hypotheses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short term</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common to experience some improvement</td>
<td>Uncertainty (re normative expectations)</td>
<td>Reduced access to medical expertise post-discharge, and expectation of (aspiration towards) self-reliance, increase anxiety and uncertainty about when to seek help, and one’s own best actions in assisting recovery. Frequent visits for care and rehab. soon after discharge mitigate this.</td>
</tr>
<tr>
<td>Recovery often slower than hoped – experience of fatigue and weakness</td>
<td>• rate of progress</td>
<td>Information, training, patient education reduce uncertainty, thus anxiety, and improve self-reliance.</td>
</tr>
<tr>
<td>Worries about what is ‘normal’ in terms of recovery experience</td>
<td>• unanticipated symptoms</td>
<td>A degree of certainty is established about the level of change.</td>
</tr>
<tr>
<td>Older people particularly appreciate frequent visits soon after discharge</td>
<td>Uncertainty (re own role)</td>
<td>Re-evaluation of life goals, and life planning for the new situation.</td>
</tr>
<tr>
<td><strong>Longer term</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working out how to manage</td>
<td>Change</td>
<td></td>
</tr>
<tr>
<td>How to preserve control over the most important things</td>
<td>• Active coming to terms with change</td>
<td></td>
</tr>
<tr>
<td>Accepting what must be given up</td>
<td>Control/autonomy</td>
<td></td>
</tr>
<tr>
<td>Older people may conceal decisions about the balance of risks they have chosen</td>
<td>Trade-off of risk against life choices</td>
<td></td>
</tr>
<tr>
<td><strong>Hospital staff perspectives</strong></td>
<td>Lack of participation attributed to unwillingness of patients to engage</td>
<td>Staff are not aware of older people’s perspectives on why they do not participate.</td>
</tr>
<tr>
<td>Staff generally believe older people do participate in discharge planning (as much as they want to)</td>
<td>Risk management and safety are priorities at discharge, and within assessment</td>
<td>Discharge plans made in hospital do not take account of longer term life-planning issues.</td>
</tr>
<tr>
<td>Discharge influenced by factors other than patient readiness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical care at times a priority over discussion, particularly re discharge</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6.9 The implications of this synthesis for services to older people

This project is primarily methodological, and chapter 7 draws the lessons for the field of systematic reviews. However, it would be inappropriate not to comment here on the implications for the topic selected for qualitative synthesis. Again, the reader should recall the limitations of this review: (a) this was not a comprehensive systematic review; (b) socio-demographic data was often lacking and that it is therefore difficult to specify the populations to which conclusions apply; and (c) specific gaps were identified in relation to studies of the views of older people with severe cognitive impairment, communication difficulties, or whose admission involved a minor condition not requiring aftercare. With these caveats, there are several major messages for the topic of discharge of older people.

First, it is clear that studies of older people's views are available, can be synthesised, and offer perspectives that either add to or qualify the review by Parker et al (2002), which focused solely on controlled trials of methods of improving hospital discharge. In particular, the studies add to our ability to explain the mechanisms that might be at work in the discharge schemes reviewed by Parker et al. For example, the Early Discharge Rehabilitation Service described in Cunliffe et al (2004) involved intervention in hospital and at home with continuity of staff between these situations. Parker et al demonstrated that these conditions are attributes of discharge interventions that work to reduce re-admissions. From an older person's perspective such interventions seem, from our evidence, to provide a means of reducing anxiety and uncertainty post-discharge, as well as providing continuity of support while people work through and manage longer-term changes.

As we have seen, people do experience uncertainties and anxieties before discharge, and these relate both to the future course of their health and medical condition, and to questions about how and whether they will manage in their specific home environment. These questions are, of course, integrally linked, and, although information and education before discharge can allay some of these concerns, the issues are unlikely to be fully resolved until after the person has returned home. Once home, older people's actual experiences, and reflections on their situation and condition, mean that the questions they need to ask, and the arrangements they wish to make, may well become clearer to them. At this stage, some continuity of staff, who can provide or assist with access to appropriate services, is much valued. Equally, the provision of information and training for older people prior to discharge about how to manage their condition may equip them with the tools and confidence, both to cope, and to seek assistance if needed. Specific educational interventions have been shown to work for older people who have to manage a chronic condition and the findings of our studies of older people (for example, in respect of medication) reinforce the idea that good information and active training can contribute to older people's confidence in managing their care and thus the reduction of anxiety and uncertainty.

However, the synthesis also points to a completely different kind of understanding of the discharge process than that which underpins the traditional review. The synthesis suggests that older people view discharge as simply an integral part of the process of coming to terms with the impact of illness on life planning. Experiencing illness, being treated in hospital and leaving hospital is therefore a major event or process that
threatens self-sufficiency and control over one's life, particularly if complete physical recovery is not expected in the longer term.

This concept of illness and life planning is captured particularly in the studies that describe an illness trajectory, expectations of being able to control events, dealing with loss, planning how to cope, wishing to avoid being a burden, and having sufficient information to know whether things are going wrong.

The synthesis shows that, while health staff may know more about the physical effects of illness and its likely impact on daily life, they know much less about what this means for older people and their life plans. Older people know their own life plan, and what they fear might be the impact of the illness, but need carefully delivered information, and carefully constructed opportunities, to review their life plan in the light of their illness and to make their own plans accordingly. They also need the recognition that discharge might involve far more important issues (to them) than safety per se, and far more than being expected to accept passively any limitations consequent on illness. The synthesis shows that, in older people's eyes, coming to terms was not a passive process of acceptance but an active process of working out how to manage, and how to preserve control over the most important things while accepting what must be given up.

Thus the value of this qualitative synthesis for the topic of older people and hospital discharge is that it reveals some of the mechanisms underpinning successful interventions to support older people after discharge, and that it points to a life-planning framework for understanding the impact of illness, admission and discharge. This life-planning framework is completely missing from the original review, and yet it has the capacity to change profoundly the construction of interventions to support older people through their experience of illness and hospital.

The implication is that any future systematic review of this field would be more relevant if it incorporated (a) qualitative synthesis of non-intervention studies and (b) attention, in the synthesis of intervention studies, to the kind of outcomes and issues revealed in the qualitative synthesis.
7. Methodological conclusions

The application of qualitative synthesis to systematic reviews is undoubtedly a demanding task. It adds complexity at every stage of the systematic review process – in searching, deciding inclusion criteria, data extraction, quality appraisal and synthesis. It demands considerable time, and a great deal of perseverance. There must therefore be a strong rationale for making systematic reviews more complicated.

The classic response in terms of systematic review methods is that the kinds of primary studies included in systematic reviews must be appropriate to the research question. However, this takes us part of the way only, since it begs the question of whether the right research questions have been asked in the first place. At the outset of this report, we suggested that key questions about the effectiveness of interventions cannot be answered solely by examining effect sizes from controlled studies.

This means that the first part of the rationale for engaging with qualitative synthesis is a commitment to asking a wider range of questions than those addressed by systematic reviews that focus solely on controlled studies. If those interested in systematic reviews as a central element in evidence-based policy and practice want to know why interventions do or do not work, and whether they offer people the outcomes they want, they will need to engage with qualitative synthesis.

In the current review, the synthesis uses findings about older people’s views to provide information about the kind of interventions they are likely to find relevant (particularly those employing an information and education approach), and that therefore would repay further investment and testing. Such testing would of course include controlled trials, but should be accompanied by the collection of data on the processes of intervention (as does the controlled trial by Cunliffe et al, 2004). In this sense the qualitative synthesis qualifies, or adds information to the traditional review by Parker et al (this is what, in relation to the role of qualitative research in evidence-based policy and practice, Popay and Williams, 1998, call the ‘enhancement model’). However, the synthesis also demonstrates an important new understanding of the issues involved by showing the way illness, admission and discharge are linked to older people’s life planning, and, in particular, to their plans to retain control and independence. In this sense, the synthesis is an example of what Popay and Williams call the ‘difference model’, that is, it provides a different kind of understanding not available through other methods.

Thus the power of the qualitative synthesis lies in the way it both enhances the traditional review of controlled studies and provides new ways of understanding the issues and new avenues for investigation.

The value of the qualitative synthesis depends on the credibility of the analytic methods, particularly in the relationship between the findings and the evidence. The qualitative synthesis, or meta-ethnography, cited by Campbell et al (2003) on the experiences of people with diabetes, and that by Britten et al (2002) on lay meanings of medicines, suggest that the value of the approach lies in the fact that it generates
explanations and hypotheses that go beyond those reported in the primary studies: the conclusions are uniquely available as a result of synthesis.

In terms of the results of the current synthesis, the authors are, as social researchers, wary of claims to have discovered new knowledge, and we would in the first instance place great emphasis on the way that findings are strengthened by rigorous and transparent methods of cross-referencing them across a set of primary studies. The synthesis amplifies and grounds the findings from any one study, on the basis of a systematic selection of studies containing primary evidence. In our view, this provides a much firmer basis for conclusions than a traditional literature review, which lacks such transparent and rigorous methods and often includes a wide variety of studies other than those that report direct evidence.

However, as we have developed the synthesis, particularly in response to external comment, we have reached the view that some of the lines of argument and third-order interpretations reported in Chapter 6 do go beyond the understanding that can be generated from a narrative review. In particular, we would draw attention to the relationship between the life-planning perspective and the role of information and education, to the discrepancy between staff and older people’s views on why they do not participate more in discharge planning, and the fact that discharge plans do not take account of longer-term life-planning issues.

Of course, none of this should be stated without qualification. The current synthesis is based on a partial, rather than an exhaustive search; we have already noted lack of primary studies on key issues such as interventions to support people with severe cognitive impairment or communication difficulties; it does not include attention to older people with minor conditions who may need little assistance on their return home (but who may have much to say about the issues of life planning, independence and control); and lack of depth and detail, particularly on socio-demographic characteristics, in many of the primary studies is a serious limitation.

The last of these is perhaps the key obstacle to using qualitative synthesis more widely. The reporting of most non-intervention studies that would provide the basis for qualitative synthesis is simply not up to the job. It is unacceptable to omit basic socio-demographic details of people from whom data was collected, when and how data collection took place, and how it was analysed; yet many studies lack this information. There is also the question of depth of analysis and of reporting (so-called ‘thick’ description). We have noted that some techniques of qualitative synthesis (particularly reciprocal translational analysis and refutational synthesis) call for depth of detail in order to test whether an emerging category of synthesis is valid across studies. One example in the current study is where there are reports of difficulties in communication, but no detail is given about what is meant by the term (even to the point that it may be difficult to tell whether it means communication between staff or between staff and older people). Only if greater care is taken in defining, analysing and reporting such detail will it be possible to make greater progress in qualitative synthesis.

Despite these limitations, our view is that qualitative synthesis of the kind reported here offers an essential addition to the creation of the knowledge base for policy and
practice, particularly by providing access to information on why interventions work and whether they respond to the concerns of people who use services. Qualitative synthesis may also draw attention to new ways of understanding how people behave and what they expect from services. Qualitative synthesis should thus become an integral element in the conduct of systematic reviews to underpin evidence-based policy and practice in social care.
References


Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G. and Oakley, A. (2004) 'Applying systematic review methods to studies of people's views: an example from public health research', *Journal of Epidemiology and Community Health*, vol 58, no 9, pp 794-800.

Text Detective compiled by David Reeves. Note that other qualitative data analysis programmes such as Atlas/ti and Nudist also offer this facility.


## Appendix A: Databases and search strategies

### Studies on older people’s discharge from hospital

<table>
<thead>
<tr>
<th>Database</th>
<th>Search terms</th>
</tr>
</thead>
</table>
| CareData 1999-2004 | Keywords = (OLDER PEOPLE/VERY OLD PEOPLE) & (HOSPITALS) & DISCHARGE  
                        | Freetext in title or abstract or full-text = ((old people)/(older people)/
                        |   (elderly)/(very old people)) & (hospital*) & (discharge*) & (opinion*/
                        |   view*/survey*/interview*)  
                        | Freetext in title or abstract or full-text = ((old people)/(older people)/
                        |   (elderly)/(very old people)) & (hospital*) & (discharge*)  
                        | Searched 16/07/04  
                        | Keywords = (INTERMEDIATE CARE) & (OLDER PEOPLE)  
                        | Freetext in title or abstract = (intermediate care) |
| CareData 1994-98 | Keywords = (OLDER PEOPLE) & (DISCHARGE)  
                        | Searched 27/04/04  
                        | AgeInfo 1999-2004 | Keywords = (DISCHARGE [HOSPITALS])  
                        | Freetext in title or abstract = (DISCHARGE [HOSPITALS])  
                        | Searched 22/04/04  
                        | Searched 04/08/04  
                        | Freetext = (intermediate care)  
                        | Searched 27/04/04  
                        | Freetext = (discharge* & hospital* & interview*)  
                        | Searched 04/08/04  
                        | Freetext = (discharge* & hospital* & (opinion*/view*/qualitative/ 
                        | satisfaction))  
                        | AgeInfo 1994-98 | Searched 27/04/04  
                        | Freetext = (discharge* & hospital* & (opinion*/view*/qualitative/ 
                        | satisfaction))  
                        | PsycInfo 1999-2004 | Keywords = (ELDER CARE) & (HOSPITAL DISCHARGE)  
                        | Freetext in title or abstract or full-text = ((INDEXED AGE GROUP 'AGED' 
                        | or 'VERY OLD') & keywords = (HOSPITAL DISCHARGE)&((ATTITUDE MEASURES)/(ATTITUDE MEASUREMENT)/
                        | (HEALTH ATTITUDES)/(CLIENT SATISFACTION)/(EXPERIENCES, 
                        | EVENTS)/(CLIENT PARTICIPATION))  
                        | Searched 20-22/04/05  
                        | Keywords = (DIAGNOSTIC-INTERVIEW-SCHEDULE)/(INTAKE- 
                        | INTERVIEW)/(INTERVIEW SCHEDULES)/(INTERVIEWING) 
                        | /INTERVIEWS)/(PSYCHODIAGNOSTIC INTERVIEW) or 
                        | (STRUCTURED-CLINICAL-INTERVIEW)  
                        | (Index age group ‘aged’ or ‘very old’) & keywords = (HOSPITAL 
                        | DISCHARGE)&((ATTITUDE MEASURES)/(ATTITUDE MEASUREMENT)/
                        | (HEALTH ATTITUDES)/(CLIENT SATISFACTION)/(EXPERIENCES, 
                        | EVENTS)/(CLIENT PARTICIPATION))  
                        | (Index age group ‘aged’ or ‘very old’) & keywords = (HOSPITAL 
                        | DISCHARGE)
DISCHARGE) & ([(ATTITUDE MEASURES)/(ATTITUDE MEASUREMENT)/(HEALTH ATTITUDES)/(CLIENT SATISFACTION)/(EXPERIENCES, EVENTS)/(CLIENT PARTICIPATION)]/[(DIAGNOSTIC-INTERVIEW-SCHEDULE)/(INTAKE-INTERVIEW)/(INTERVIEW SCHEDULES)/(INTERVIEWING)/(INTERVIEWS)/(PSYCHODIAGNOSTIC INTERVIEW) or (STRUCTURED-CLINICAL-INTERVIEW)])

(Index age group ‘aged’ or ‘very old’) & keywords = (HOSPITAL DISCHARGE) & ([(DIAGNOSTIC-INTERVIEW-SCHEDULE)/(INTAKE-INTERVIEW)/(INTERVIEW SCHEDULES)/(INTERVIEWING)/(INTERVIEWS)/(PSYCHODIAGNOSTIC INTERVIEW) or (STRUCTURED-CLINICAL-INTERVIEW)])

Freetext = (old* people/elder*) & (hospital) & (discharge*) & (view*/opinion*/experience*/survey*/attitude*/satisf*/perception*/qualit*)

Freetext = (old* people/elder*) & (hospital) & (discharge*) & (old* people)

Freetext = (hospital) & (discharge*) & (elder*)

PsycInfo Searched 28/04/04

1994-98 Freetext = (hospital) & (discharge*) & (elder*)

Keywords = (HOSPITAL DISCHARGE) & (index age group ‘aged’ or ‘very old’)

Social Sciences Web of Knowledge interface, searched 21/04/04

Freetext = ((old* people)/(elder*)) & hospital & discharge* Freetext = (opinion*/view*/experience*/interview*/attitude*/satisf*/perception*/qualit*)

Freetext = ((old* people)/(elder*)) & hospital & discharge* & (opinion*/view*/experience*/interview*/attitude*/satisf*/perception*/qualit*)

Social Sciences Citation Index Searched 28/04/04

Citation Index 1994-98 Freetext = ((old* people) / (elder*)) & hospital & discharge* 1994-98 Freetext = (opinion*/view*/experience*/interview*/attitude*/satisf*/perception*/qualit*)

(Freetext = ((old* people)/(elder*)) & hospital/discharge* & (Freetext = (opinion*/view*/experience*/interview*/attitude*/satisf*/perception*/qualit*))

MEDLINE OVID interface, searched 26/04/04

Keywords = (exp ** "Aged, 80 and over"/or exp *Aged/or olderpeople.mp.) And & (exp *Patient Discharge/or hospital discharge.mp.) and & ((qualitative research.mp. or exp *Qualitative Research/) or (interviews.mp. or exp *INTERVIEWS) or (patient satisfaction.mp. or exp *Patient Satisfaction/))

Freetext = ([old$ people.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]) or (elder$.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]) or (aged.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]) and (hospital$s) and (discharge$s) and ((opinion$.mp. [mp=title, original title, abstract, name of substance,
CINAHL OVID interface, searched 27/04/04
1999-2004 Keywords = (exp *Health Services for the Aged/or exp */Aged, 80 and Over/*or exp *Aged/or exp *Gerontologic Care/)
Keywords = (exp *Early Patient Discharge/or exp *Discharge Planning/or exp *Patient Discharge/or hospital discharge.mp).
Keywords = (qualitative research.mp. or exp *Qualitative Studies/ interview.mp. or exp *Interviews/)
Keyword = (exp *Consumer Participation/)
Keyword = (exp *Patient Satisfaction/)
Keywords = (exp *Health Services for the Aged/or exp */Aged, 80 and Over/*or exp *Gerontologic Care/ and (exp *Early Patient Discharge/ or exp *Discharge Planning/or exp *Patient Discharge/or hospital discharge.mp.) and ((qualitative research.mp. or exp *Qualitative Studies/) or (interview.mp. or exp *Interviews/) or (exp *Consumer Participation/) or (exp *Patient Satisfaction/))

SIGLE SilverPlatter WebSPIRS interface, searched 27/04/04
Appendix B: Studies identified through search processes


Using qualitative research in systematic reviews: Older people’s views of hospital discharge

Systematic reviews have become a cornerstone of evidence-based policy and practice in modern social care. Current practice in systematic reviewing focuses on quantitative studies, yet important additional perspectives can be gained by incorporating qualitative studies.

In this report SCIE uses the example of older people’s views on discharge from hospital to provide a worked example of combining findings from qualitative studies and draws out key messages for systematic reviewing.

This publication is available in an alternative format upon request.