PSSRU

Housing LIN

Evaluation of the extra care housing initiative:

PSSRU technical report

Robin Darton, Theresia Bäumker, Lisa Callaghan and Ann Netten

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Acknowledgements

Background

A central principle underlying the policy of recent governments has been to help people maintain their independence in their own homes for as long as possible. In particular, there has been a long-standing policy to reduce admissions to care homes. More recently, policies have emphasised the personalisation of services, with the aim of giving people greater choice and control over the services they receive (Department for Communities and Local Government, 2008; HM Government, 2010). Increasingly, housing has been seen as essential in the development of effective community care services, but housing and social services have tended to develop separately (Audit Commission, 1998; Oldman, 2000). The previous government identified a need for partnership between health, housing and social services for the development of successful community care services in its 1998 White Paper (Cm 4169, 1998), and this was reinforced in subsequent policy documents (Office of the Deputy Prime Minister, 2006; Department for Communities and Local Government, 2008; Cm 7673, 2009), and by the Coalition Government in 2010 (Department of Health, 2010).

In 2003, the Department of Health announced a new fund to support the development of extra care housing (Department of Health, 2003b). The Extra Care Housing Fund was intended to develop innovative housing with care options for older people and stimulate effective local partnerships between health, social services and housing agencies and providers (Department of Health, 2003a). 'Extra care housing' has become the preferred term for housing integrated with care, although other terms have been used, including 'very sheltered housing', 'care plus', 'assisted living' and 'category 2.5 accommodation' (Laing & Buisson, 2010). It aims to meet the housing, care and support needs of older people, while helping them to maintain their independence in their own private accommodation.

Extra care housing covers a range of specialist housing models. Although there is no agreed definition, Laing & Buisson (2010) suggest that it can be recognised by several characteristics: it is primarily for older people; the accommodation is (almost always) self-contained; personal care can be delivered flexibly, usually by staff based on the premises; support staff are available on the premises for 24 hours a day; domestic care is available; communal facilities and services are available; meals are usually available, but are optional and charged for only when taken; it aims to be a home for life, and to allow people to age in place; and it is owner-occupied or offers security of tenure if rented. Extra care housing offers a variety of housing tenures, and can enable people to safeguard their financial assets by purchasing or part-purchasing their accommodation.

A distinction needs to be made between smaller extra care schemes, typically with 40 or more units of accommodation, and larger retirement villages, with 100 or more units (Evans, 2009). Retirement villages provide a wider range of social and leisure activities and more accommodation for purchase. Individuals are encouraged to move in at a younger age to stimulate the development of a mixed or balanced community of interests and abilities.

The Extra Care Housing Fund was originally part of the Department of Health's Access and Systems Capacity Grant programme, and provided £87 million capital funding for local authority social services departments and housing associations to help create up to 1,500 places between 2004–2006 (£29m for 2004-05 and £58m for 2005-06) (Department of Health, 2003b). Another £140 million was

allocated between 2006 and 2010 (Department of Health, 2005; Department for Communities and Local Government, 2008). Around 450 bids were submitted altogether, and 86 were successful. The successful schemes included smaller schemes and larger retirement villages, and included both new build and remodelled schemes, although some of the new build schemes involved the upgrading/ remodelling of existing buildings as part of the development.

Extra care housing has also been viewed as a possible alternative to moving into a care home (Cm 6499, 2005). Indeed, some have advocated the complete re-provision of residential care by developing extra care (Appleton and Shreeve, 2003; Housing Learning & Improvement Network, 2003; Department of Health, 2004). The Care Standards Act 2000 and the Regulation of Care (Scotland) Act 2001 removed the legal distinctions between residential and nursing homes, which became 'care homes' from 2002. However, homes providing nursing care are still distinguished from those providing personal care, and extra care is likely to have more effect on homes providing personal care, since care homes will still be needed for residents requiring high levels of nursing care or continuous monitoring (Laing & Buisson, 2010).

A number of studies of sheltered housing and extra care schemes have been undertaken, but these have often concentrated on individual developments. Three large-scale studies were undertaken to provide systematic comparisons of sheltered and very sheltered schemes (Butler et al., 1983; Tinker, 1989; McCafferty, 1994), but these are now rather dated. Recently, Croucher and colleagues have published a comparative study of seven schemes (Croucher et al., 2007), and Evans and Vallelly have undertaken studies including a number of schemes managed by one housing provider (Vallelly et al., 2006; Evans and Vallelly, 2007). However, at the time, there was a dearth of large-scale studies of this type of provision and very little information about cost-effectiveness (Croucher et al., 2006).

Participation in an evaluation was a condition of receiving support from the first two rounds of the Extra Care Housing Fund. The PSSRU study was the first evaluation of specialised housing supported by the Department of Health. It aimed to examine the development of the schemes from their implementation, and to follow the residents' experiences and health over time. The PSSRU has undertaken a number of studies of care homes and their residents (Bebbington et al., 2001; Netten et al., 2001, 2002; Darton et al., 2006, 2010). One of the aims of the evaluation was to compare costs and outcomes with those for residents moving into care homes, using equivalent data from studies of care homes and their residents.

Initial findings for the first schemes that opened were presented in Darton et al. (2008), and early comparative findings for those that opened in 2006–2007, focusing on the support of people with dementia, were presented in Darton and Callaghan (2009). More broadly, the evaluation provided an opportunity to collect research evidence about the process and impact of new approaches to providing accommodation and care for older people. In addition to the work funded by the Department of Health, the PSSRU was awarded funding for six further studies that complemented the main evaluation. These are described in the section entitled 'linked projects', below. Details of the outputs from the evaluation are shown in Appendix G. In addition, a website was created to provide links to the outputs from the evaluation (www.pssru.ac.uk/projects/echi.htm).

Aims and objectives

The objective of the evaluation was to evaluate new build schemes for older people that received capital funding from the Extra Care Housing Fund in the first two rounds, from 2004–2006. The evaluation aimed to examine the development of the schemes from their implementation, and to follow the residents' experiences and health over time. A particular feature of the evaluation was to compare explicitly costs and outcomes with those for residents moving into care homes.

More broadly, the evaluation provided an opportunity to collect research evidence about the process and impact of new approaches to providing accommodation and care for older people. The objectives were to identify:

- The models and characteristics of extra care housing schemes, their advantages and disadvantages
- Circumstances and factors that influence the feasibility and success of the schemes
- Views, experiences and characteristics of the people who live in the schemes
- Views, experiences and characteristics of care and support staff
- The impact of design characteristics on the success of the schemes
- The role of and interaction with the local community
- Cost-effectiveness of different models
- Long-term outcomes for individuals, such as their health and quality of life
- The role and potential of such schemes in the overall provision of care for older people (including residential care, and day and domiciliary care)

The project outline is included in Appendix A.

Research timetable

As noted above, the evaluation covered extra care schemes that received funding from the Extra Care Housing Fund in the first two rounds, from 2004–2006. The successful bidders were announced in February 2004 and February 2005, respectively, and the Department of Health requested that the PSSRU include 22 schemes in the evaluation, 11 from the first round and 11 from the second round. Details of the schemes to be included were supplied to the PSSRU in May 2004 for the first round and in March 2005 for the second round. In the initial bids the dates of practical completion for the 22 schemes ranged from November 2005 to October 2007, as shown in Table 1, below. However, all of the schemes experienced delays. In five cases the building was completely re-designed or replaced by a different building on a new site, and in two of these cases the housing provider was changed.

The main evaluation was conducted during the PSSRU's five-year funding period, from 2006–2010, to allow the tracking of the outcomes for the older people who moved into the schemes. At the beginning of the evaluation period, the schemes were expected to open over a period of 18 months, from April 2006 to October 2007. However, in Summer 2007 the opening timetables for the schemes were reviewed in consultation with the Department of Health, and it was agreed to restrict the main evaluation to the 19 schemes that were due to open by Summer 2008, in order to provide sufficient time to undertake the longitudinal follow-up of residents over a period of at least 18 months from moving in and to complete the analyses and prepare a final report within the research timetable. The schemes that were excluded from the main evaluation were offered the opportunity to participate by collecting comparable information, as far as timing allowed, but none took up the opportunity to do this. In the event, the 19 schemes that were included in the evaluation opened between April 2006 and November 2008, as shown in Table 1.

Preliminary work for the study began in the latter part of 2002 with discussions of the research issues and the preparation of a paper on alternatives to residential care provision (Darton and Netten, 2003). This was followed by meetings with experts in housing issues in local authorities, housing providers, including housing associations and private providers, and government non-profit agencies, which took the form of tape-recorded, focused interviews. Service users living in two local authority housing schemes and one private development providing extra/enhanced care in Kent were also consulted. The meetings with service users consisted of a short presentation outlining the work of the PSSRU in the field of housing and care, which explained that the government was funding new extra care schemes around the UK, and that the researchers would be evaluating these schemes. Participants were then asked for their opinions on what people should be asked about moving into extra care housing. Draft questionnaires and other materials were developed in consultation with service users prior to the start of the main evaluation. The preliminary exploration of research issues and background literature led to the preparation of a chapter in an edited volume focusing on current evidence on alternative housing and care arrangements (Darton and Muncer, 2005). In addition, two separate studies were undertaken in 2005–2006 to examine the development of extra care housing in a sample of authorities (Dawson et al., 2006) and older people's perceptions of control in care homes and extra care housing (Towers, 2006). The project outlines for these two studies are included in Appendix A.

Following receipt of copies of the bids prepared by the schemes that were to be included in the evaluation, the research team prepared systematic summaries of the information in the bids in order to guide the research process. A meeting for representatives of all the schemes and members of government and other agencies was held in October 2005 in order to introduce the research team and describe the proposed evaluation. The meeting included small group discussions during which the delegates were asked to identify potential research questions and practical issues that might arise during the evaluation. Unfortunately, a number of delegates from the North of England were unable to reach the meeting due to travelling problems, but the meeting was successful in raising questions about the evaluation and housing and care issues more generally.

Beginning in January 2006, individual meetings were held with representatives of each scheme to outline the evaluation, obtain an update on the scheme plans and timetable, and discuss the data collection process and consent procedures. Prior to the meeting, the research team prepared a document based on the information contained in the bid for funding to summarise this information in a systematic manner, and this document was updated in the light of the discussion at the meeting. An important part of the meeting involved the examination of a draft questionnaire about resident characteristics, to identify whether the assessment process would generate the information required or whether changes to the questionnaire were necessary. In addition, the representatives were asked whether they could help in identifying possible candidates for the role of local interviewer or useful contacts. Local interviewers were recruited to liaise with each scheme, and to assist in data collection, including helping residents to complete questionnaires when required.

Before the scheme opened, a second meeting was held to introduce the local interviewer, where possible, and to discuss the detailed arrangements for the data collection process. In a small number of cases, meetings were also held with residents or potential residents of the schemes to discuss the research. However, the nature of the assessment process and the practicalities of contacting residents while they were in the process of a major change in their housing arrangements usually meant that residents could not be approached until after they had moved in, and the local interviewer was responsible for making contact with residents and encouraging participation in the research.

Shortly after moving into the scheme, data were collected directly from residents about their experiences of moving and their expectations, and indirectly about their demographic characteristics and care needs, drawing on the information collected in the assessment process. Similar information was collected about residents six, 18 and 30 months after moving in, to identify changes over time. It had been intended that a further follow-up would be undertaken at 42 months, following the methodology used in a previous longitudinal survey of admissions to care homes (Bebbington et al., 2001), but the decline in response by 30 months indicated that this would be unlikely to yield a large enough sample to be worthwhile. The fieldwork was continued until the end of May 2010, but for the schemes that opened in 2008, and one that opened in late 2007, the number of follow-ups was determined by the research timetable. Eleven of the 19 schemes had 30 month follow-ups completed for some of their residents, and a further five had 18 month follow-ups. In the remaining three cases, only six month follow-ups were obtained. However, fieldwork problems were experienced in a number of schemes, which reduced the number of follow-ups achieved.

The schemes

Table 1 shows details of the 22 schemes that were originally expected to be included in the evaluation, and Figure 1 shows the locations of the schemes. However, as noted above, all of the schemes experienced delays in opening. In five cases the building was completely re-designed or replaced by a different building on a new site, and in two of these cases the housing provider was changed. Following a review of the opening timetables for the schemes in Summer 2007, it was agreed with the Department of Health to restrict the main evaluation to the 19 schemes that were due to open by Summer 2008, in order meet the research timetable.

Four of the 22 schemes were villages, with more than 100 units of accommodation, including one of the three schemes excluded from the main evaluation. A number of the schemes provided intermediate care, designed to help people make the transition from hospital care back to their own homes. These individuals were not included in the evaluation, which was restricted to the long-term residents. In addition, some residents moved into schemes without requiring a care assessment. In the villages, the majority of new residents did not require care services.

Table 1: Extra care schemes funded in 2004–2006 and to be included in PSSRU evaluation

Social services authority	Housing provider[1]	Original opening date[2]	Actual opening date[3]	Total units (original)[4]	Total units (final)
2004–05 (Round 1)					
Brighton & Hove City Council	Hanover HA	03/06	07/06	37	38
East Riding Council	Housing 21	01/06	04/06	39	39
London Borough of Enfield	Hanover HA	09/06	11/06	48	48
London Borough of Havering	Housing 21	04/06	08/06	62	64
Liverpool City Council[5]	Arena HA	07/06	09/08	49	49
Milton Keynes Council	ExtraCare Charitable Trust	Summer 06	06/07	250	258
Northamptonshire CC	ExtraCare Charitable Trust	01–03/06	08/06	270	270
Peterborough City Council	Axiom HA	11/05	07/06	40	40
Staffordshire County Council[5,6]	Housing 21	02/06	12/08	27	42
Stoke-on-Trent City Council[7]	Staffordshire HA	01/06	05/08	53	75
West Sussex CC (Horsham DC)	Saxon Weald Homes Ltd	03/06	07/06	40	40
2005–06 (Round 2)					
Blackburn with Darwen BC	Housing 21	04/07	11/07	48	48
Bradford Metropolitan DC	MHA Care Group	12/06	04/07	46	46
Cheshire County Council[5,8]	Arena HA	05/07	09/09	232	124
Darlington Borough Council	Hanover HA	08/07	10/07	42	42
Derbyshire County Council	Housing 21	01/06	08/08	43	43
London Borough of Ealing	Hanover HA	09/06	10/07	35	35
Hartlepool BC	Joseph Rowntree Housing Trust	10/07	08/08	225	242
North Yorkshire CC	Housing 21	11/06	12/07	39	39
Rotherham MBC	Chevin HA	07/06	04/07	35	35
Wakefield MBC[9]	Yorkshire Housing	01/07	09/07	45	45
West Sussex (Crawley BC)[10]	Housing 21	09/06	11/08	50	39

Notes:

1. The housing providers shown are those involved in the completed schemes.
2. The original opening date was that stated in the original bid as the date of practical completion.
3. For the 19 schemes included in the evaluation, the actual opening date was the date when the first residents moved in, apart from one scheme where 8 residents moved back into remodelled accommodation one month beforehand. For the three schemes excluded from the evaluation (see note 5), the opening date was the planned date of completion, as reported in Summer 2007.

4. The original size was that stated in the original bid.
5. The Liverpool, Staffordshire and Cheshire schemes were excluded from the evaluation due to delays in completion.
6. The Staffordshire scheme replaced the original 27 unit scheme.
7. The Stoke-on-Trent scheme replaced the original 53 unit scheme, and was built on a new site.
8. The Cheshire scheme replaced the original 232 unit scheme, and was built on a new site by a different housing provider.
9. The Wakefield scheme replaced the original 45 unit scheme, and was built on a new site by a different housing provider.
10. The West Sussex (Crawley BC) scheme replaced the original 50 unit scheme.

Smaller schemes
Villages

Hartlepool
Darlington

East Riding
North Yorkshire
Blackburn Bradford
Wakefield
Rotherham
Derbyshire
Stoke-on-Trent

Peterborough

Northamptonshire
Milton Keynes

Enfield
Havering
Ealing

West Sussex (Crawley)
West Sussex (Horsham)
Brighton and Hove

Note: The Cheshire, Liverpool and Staffordshire schemes were not included in the evaluation due to delays in completion.

Linked projects

In addition to the main evaluation funded by the Department of Health, the PSSRU was awarded funding for six further studies that complemented the main evaluation. These included two projects supported by the Joseph Rowntree Foundation (JRF): a study of the development of social activity and community involvement in extra care (Callaghan et al., 2009); and an in-depth study of one of the schemes to investigate and compare costs to all stakeholders before and after residents moved into extra care (Baumker et al., 2008, 2010). The study of social activity provided material which was used to update the directory for promoting social well-being, published by the Housing LIN (Evans et al., 2010). The third study was a joint project with colleagues from the University of Sheffield funded by the Engineering and Physical Sciences Research Council (EPSRC) to develop a tool for evaluating the design of housing and care environments (Lewis et al., 2010a,b).

Funding was also agreed with one of the local authorities included in the evaluation and the relevant housing provider to enable the collection of comparable information about a second scheme in the local authority (Darton and Bäumker, 2009). Finally, the Thomas Pocklington Trust has provided funding for studies of two extra care schemes for people with sight loss in Birmingham and Plymouth, in order to provide comparative information to that collected in the main evaluation. Reports of the two studies conducted in the schemes managed by the Thomas Pocklington Trust will be available in 2012.

Project outlines were prepared for five of these additional projects, and these are included in Appendix A.

Data collection

Overview

Prior to the opening of each scheme, a local interviewer (or fieldworker) was recruited to liaise with the scheme, coordinate the collection of data and undertake interviews with residents (see Appendix B). The interviewers had had experience of working with vulnerable older people, and all received training by the PSSRU (see Appendix C). An assistant for the local interviewer was also recruited for the villages. All interviewers and assistants had full Criminal Records Bureau (CRB) checks. The interviewers were issued with a comprehensive 'Resource Pack' which contained copies of the questionnaires and other documentation and detailed guidelines for the fieldwork (See Appendix C).

Two main sets of information were collected about individual entrants to the schemes included in the evaluation. First, information on the demographic characteristics and care needs of residents was collected, drawing on the information collected in the assessment process, using a questionnaire designed to correspond to one used in a recent study of admissions of older people to care homes (Darton et al., 2006, 2010) and to those used in a number of similar previous studies. The questionnaire was developed in consultation with representatives of the schemes to ensure that the information required was relevant and available to the staff involved in the application process. Similar information was collected about residents six, 18 and 30 months after moving in, to identify their current level of physical and mental functioning and their use of care services, and to identify changes over time. As noted above, it had been intended that a further follow-up would be undertaken at 42 months, following the methodology used in a previous longitudinal survey of admissions to care homes (Bebbington et al., 2001), but the decline in response by 30 months indicated that this would be unlikely to yield a large enough sample to be worthwhile.

Second, new residents were asked to complete a questionnaire about their expectations of extra care and their experiences of moving into the scheme, assisted, where necessary, by the local interviewer. This questionnaire was followed up by the study of social activity funded by the Joseph Rowntree Foundation. Six months after each scheme opened, four residents and two members of staff were interviewed in each scheme to identify the degree to which facilities were used, how much residents participated in activities, the extent of community involvement in the scheme, and the residents' involvement in the wider community. This was followed at 12 months after opening by a survey of all residents, and an interview with a subsample, to identify individual views, levels of well-being and levels of participation, and to assess the social climate of the scheme.

In addition to the collection of information about individual entrants, information was collected from the local authorities concerned and the housing associations managing the schemes about the development and operation of the schemes. In 2007, in collaboration with the Department of Health, a survey of the local authority extra care housing leads for the original 22 schemes was undertaken to monitor progress, identify changes to the original bids and identify issues and lessons learned. Responses were received for 18 of the 22 schemes. In 2009–2010, the scheme manager and the care manager in each of the 19 schemes in the main evaluation were each asked to complete a questionnaire covering the facilities, the housing and care arrangements, the staffing arrangements, the overall resident profile and charging arrangements. Information was also collected about the

financial arrangements of the schemes at the scheme level. As noted above, a central purpose of the evaluation was to compare costs and outcomes, in terms of changes in dependency and survival, with those for residents moving into care homes. The evaluation included a comparison of the overall costs of extra care and care homes, adjusting for resident characteristics such as dependency, at the level of the scheme or home. However, it was not designed to compare the cost-effectiveness of the different types of provision in terms of well-being, since comparable measures of outcome for the two forms of provision were not available.

At the end of the data collection period, the interviewers were asked to complete a questionnaire to provide information on the development of the scheme for which they were responsible, in order to identify issues that had not been covered in other ways and to help place the data collected in the evaluation in a broader context.

Copies of the data collection materials used in the main evaluation and in the study of social well-being are included in Appendix D, and information on the sources of standard questions and scales included in the questionnaires is included in Appendix E.

Ethical approval and research governance procedures

The completion of each questionnaire was subject to the consent of the resident or their representative. The initial stages of the evaluation received ethical approval from the appropriate Research Ethics Committee at the University of Kent in April 2006 (SRCEA no. 0032). However, in response to the requirements of the Mental Capacity Act 2005, which came into force for existing projects in October 2008, an application was made in June 2008 to a local research ethics committee within the NHS National Research Ethics Service to cover the case of residents who may have lacked the mental capacity to consent (Leeds (West) Research Ethics Committee, reference number 08/H1307/98). Following attendance at a meeting with the ethics committee and the submission of responses to two requests for additional information, the application was approved in November 2008. The initial application covered the stages of the research up to the 18 month follow-up, and two subsequent notices of substantial amendment were submitted in January and June 2009 to cover the proposed 30 and 42 month follow-ups and the additional studies of two schemes managed by the Thomas Pocklington Trust. In addition to the ethical review applications, the information needed to satisfy research governance requirements was provided to the local authorities concerned.

Fieldwork procedures

The local interviewer was required to visit the extra care scheme for which they were responsible regularly, to meet with residents and staff, to explain the research, to gain consent, and to undertake the data collection. They were expected to maintain contact with the scheme even in quieter times of data collection, for example by attending residents' meetings or coffee mornings. The arrangements for data collection varied slightly between schemes, depending on the particular circumstances, and the interviewers were expected to use their experience and discretion to achieve the aims of the data collection process while maintaining good relationships with residents and staff. Each local interviewer had a key contact person at PSSRU who maintained regular contact with them

to ensure that fieldwork progressed efficiently. The pay rate for the interviewers was set at a level commensurate with the level of experience expected and the requirements of the work.

Recruitment of residents

Residents were informed of the research and invited to volunteer for participation in the study by the local interviewer in each scheme. At each stage, they were invited to complete the relevant questionnaire or interview by the interviewer. Participation was entirely voluntary, and residents could choose to withdraw at any point. For residents who lacked the capacity to provide consent themselves, the local interviewer was expected to identify a consultee who could advise on behalf of that person.

Consent

When potential participants were approached to take part in the evaluation, they received an information letter explaining the research and what taking part would involve. At all stages at which consent needed to be obtained, participants were given a consent form which was explained by the local interviewer. The interviewer was available to answer any queries or concerns that the participant had, explain to them fully what they were consenting to, and make clear at all stages that participation was voluntary.

Residents who lacked capacity to consent for themselves were only included in the evaluation for the collection of information for the assessment questionnaires at the time of admission and subsequently at the six, 18 and 30 month follow-ups. Such individuals were not directly involved in the data collection.

The local interviewer took advice from the scheme manager or care manager regarding residents who might lack capacity to provide consent. Once a person was identified as being unable to consent for themselves, the scheme manager or care manager identified a person who could act as a consultee to decide whether the resident in question should take part in the research. This person was either a personal consultee or a nominated consultee, when no personal consultee was available. For the purposes of the evaluation, this could not be a member of staff, due to the organisational interest in the outcome of the research, but could be an individual's GP, an independent advocate, or a social worker. Consultees were asked for consent for access to the resident's assessment interview, and for consent for the interviewer to be able to collect equivalent information from scheme staff at subsequent follow-ups. Normally, the follow-ups were completed as an interview with the resident, with some information being gained from staff, subject to the resident's consent. If a consultee gave consent, the local interviewer interviewed an appropriate member of staff for all the information, usually the care manager.

Staff selected to be interviewed for the study of social activity at six months were approached by the local interviewer and invited to take part in the interview with a member of the research team. The content of the interview was outlined, and the process explained. At the interview, permission was requested to make an audio recording of what was said, and the participant was assured of confidentiality and their right to withdraw from the study at any time.

Risks and burdens

A potential burden to participants was the length of time that some interviews could take, since this varied depending on the abilities of the participant. However, all questions included in the questionnaires and interview schedules had been carefully considered, and were included to provide particular information needed for the evaluation. The local interviewers were sensitive to the needs of older people, and would offer to stop the interview (either completely, or until a later date) if the participant appeared fatigued.

Another risk was that participants might become upset during some of the interviews. For example, participants were asked about their well-being and quality of life in some interviews, which could be upsetting to participants, particularly if their well-being or quality of life was poor. The key to minimising the risk of upsetting participants was that the local interviewers could handle the process sensitively. They were required to have experience of working with older people in a professional capacity, and the ability to deal with situations in which a participant might become upset. If a participant became distressed, interviewers offered to stop the interview, and resume at a later date or not at all.

Finally, there was a small risk that there would be a breach of confidentiality, or a failure to maintain data security. Although all information was anonymised before it reached the PSSRU for analysis, the local interviewer for each scheme created and maintained an Excel spreadsheet linking identification (ID) numbers to the person's name. However, interviewers were instructed to keep this stored securely on their home computers, in a location that was not accessible to any other parties, and to use a file encryption programme (AxCrypt) to protect the spreadsheet.

Consent forms (which also included individuals' names alongside their ID number) were also stored securely by the local interviewer, and were only returned to the PSSRU at the end of the project, to be safely destroyed. If a third party did gain access to non-anonymous personal information, it is unlikely that the threat to the individual would be great, as all participants were living in extra care schemes which had their own security systems. Access to residents' accommodation was via key-fob access only; no person who was not a resident or member of staff at the scheme could gain unauthorised access.

Confidentiality

All questionnaires and all interview transcripts were allocated a unique ID number by the local interviewer. The questionnaires completed by residents included the person's name, but the interviewer was responsible for entering the ID number on the questionnaire and then obliterating the person's name before sending the questionnaires to the PSSRU for data capture; all documents that reached the PSSRU were anonymous. The interviewer was responsible for maintaining a separate list linking the names of the individuals to the ID number. When questionnaires were delivered to the PSSRU for data processing, a secure method, such as Post Office Special Delivery, was used. Individual arrangements were made for the secure storage of completed questionnaires by the local interviewer before delivery to the PSSRU and, once the questionnaires were received at the PSSRU, they were placed in secure storage.

It was possible that a participant might disclose information during an interview that required action to be taken. In fact, very few such situations arose. If something was disclosed which gave serious cause for concern for a participant's well-being, such as indications of abuse or neglect, the local interviewer was instructed to alert their PSSRU contact person. The situation would then be discussed with the chief investigator, who would take the decision as to what action should be taken. If it was decided that action needed to be taken, and the confidentiality of the information broken, this would first be discussed with the participant in question.

There could also have been issues raised by a resident which were not as serious, but nonetheless caused concern. For example, the resident might have had complaints about the care that they were receiving. In these situations, the local interviewer would encourage the resident to go through the complaints procedures in place in their scheme. Local interviewers were instructed to make themselves familiar with the complaints procedures in place in their scheme.

Key data collection issues

Setting up the research

Where possible, the local interviewer was in place at the time of the scheme opening, so that s/he could get to know the staff and residents, and explain the research to them. The first wave of data collection was designed to capture residents' health and needs-related circumstances on admission, along with their experiences and expectations on moving, so it was important that data collection began soon after opening. However, some schemes were unwilling for this to happen since it was a very busy time for them, with the result that the research could take some time to begin.

Collection of assessment information on admission

The collection of assessment information involved the transfer of information onto a standardised form designed by PSSRU. In some cases, social services/care managers offered to collect consent for this part of the research, and in some cases to complete the forms themselves alongside their allocations process. However, this did not generally work well. The process of gaining consent was not generally successful, and it was found to be better for the local interviewer to gain consent either at a scheme meeting, or by visiting residents individually. Furthermore, social services or care staff did not generally have time to complete the assessment form. In some cases this resulted in delays, because when social services or care staff were unable to complete the form, the local interviewer needed to start from scratch.

In addition, residents with lower levels of disability could enter the scheme without passing through the local authority social services assessment procedure. This was mainly an issue in the villages, where a minority of residents received an assessment. The information was only obtained for those who received an assessment, and was not obtained for those acting as live-in carers or who did not require care services.

Self-completion 'Moving In' questionnaire

This was designed as a self-completion questionnaire, which participants would complete themselves, with support from the local interviewer as necessary. However, the frailty of many of the

residents in extra care, particularly in the small schemes, meant that the local interviewer often needed to complete this questionnaire with residents, resulting in a longer data collection time.

Collection of follow-up information

Initially, it had been expected that schemes would automatically review their residents at set intervals, and a form similar in format to the assessment questionnaire was designed for completion by the local interviewer from records held at the scheme at six, 18 and 30 months. However, it became clear that this was not the case, and that the kind of information needed was not routinely collected by schemes. As a result, the assessment questionnaire had to be redesigned as an interview to be completed with the resident, with some sections to be completed by staff, subject to the resident's consent.

The practicalities of arranging data collection in the schemes meant that the follow-ups were not always completed at the nominal times of six, 18 and 30 months, particularly the six month follow-up. Thus, analyses of changes over time reflected average changes approximately at the nominal time points.

In a small number of cases, the follow-ups were obtained without an initial assessment, but for the majority of residents who did not receive an initial assessment, mainly in the villages, the information collected was limited to their expectations of extra care and their experiences of moving into the scheme. The interviewers were asked to follow-up residents who had started to receive care services sometime after moving into the scheme and to collect assessment information at that point. However, the majority of residents who were likely to be affected were living in the villages, and the interviewers were usually unable to obtain the necessary information to include those whose status had changed.

Data preparation

A variable specification was created for each questionnaire using a consistent coding scheme and variable labelling scheme across questionnaires, based on the formats employed in the SPSS/PASW computer program. The data collected in the questionnaires were entered into a specially-designed Access database which was designed to generate files that could be exported into SPSS/PASW data files with the codes defined in the variable specifications. The statistical analysis was undertaken using various versions of the SPSS/PASW computer program (most recently release 18 (SPSS Inc., 2009)) and the Stata 10 computer program (StataCorp, 2007).

A number of standard questions and scales were included in the questionnaires, as shown in Appendix E. These included two summary measures of physical and cognitive functioning that had been computed in previous studies of care home residents. Physical functioning was measured by the Barthel Index of Activities of Daily Living (Mahoney and Barthel, 1965; Collin et al., 1988), with scores ranging from zero (maximum disability) to 20 (minimum disability). Cognitive functioning was measured by the Minimum Data Set Cognitive Performance Scale (MDS CPS) (Morris et al., 1994), with scores ranging from zero (intact) to 6 (very severe impairment). The Barthel scores were also grouped into five categories (0–4, 5–8, 9–12, 13–16, 17–20), following Granger et al. (1979), but with an additional subdivision of the scores from 13–20.

The computation of the Barthel Index and the MDS CPS involved a degree of approximation, as shown in Appendix F. However, the same questions and computer algorithm were used for the previous studies of care home residents, and therefore the approximate versions of the two measures were equivalent for each of the studies. The computation of the Barthel Index involved equating the questions used in the questionnaires to the original questions developed by Mahoney and Barthel. The majority of the questions used in the computation of the MDS CPS were equivalent to those developed by Morris et al., although the question wording had been simplified and the 'eating' item had four rather than five categories. In addition, the 'comatose' item was omitted in all of the studies. However, the exclusion of this item does not affect the construction of the scale in practice (Bebbington et al., 2001).

Response

Among the 19 schemes, the three villages accounted for 770 units of accommodation and the 16 smaller schemes accounted for 716 units, a total of 1,486 units. Excluding the accommodation designated for intermediate care and the accommodation in the villages for people who did not require care services reduced the total to 909 units.

Over the period of the evaluation, 1,894 residents were identified, including those who moved into accommodation vacated by the previous resident. Information was obtained from the assessments for 817 individuals, and a resident questionnaire was obtained for 1,182 individuals. Follow-up information was collected for 468 individuals at six months, 261 at 18 months and 130 at 30 months. In a small number of cases, the follow-ups were obtained without an initial assessment, and these have been excluded from the analyses. Table 2 shows the overall response, including the response to the questionnaires completed in the study of social activity, and summarises the number of exclusions recorded. However, it should be noted that the exclusions could occur at any stage in the fieldwork process and so cannot be used to calculate a response rate for individual questionnaires. Table 3 shows the number of questionnaires completed for each scheme, and Table 4 shows the number of residents with each questionnaire in the sequence according to the final questionnaire completed. Thus, 218 residents had a six month follow-up as the final questionnaire, 157 had an 18 month questionnaire as the final questionnaire, and 123 had a 30 month questionnaire as the final questionnaire. Eleven of the 19 schemes had 30 month follow-ups completed for some of their residents, and a further five had 18 month follow-ups. In the remaining three cases, only six month follow-ups were obtained. For the schemes that opened in 2008, and one that opened in late 2007, the number of follow-ups was determined by the research timetable, and a dash in the relevant columns of tables 3 and 4 identifies cases where no follow-up could be obtained. However, fieldwork problems were experienced in a number of schemes, which reduced the number of follow-ups achieved.

Table 2: Response

	Number
Number of schemes	19
Number of individuals identified	1894
Resident questionnaires:	
Information about Residents at Assessment (D02)	817
'Moving In' questionnaire (D03)	1182
Information about Residents Six Months After Moving In (D04)	468
Social well-being at 12 months questionnaire (D09)	604
Social well-being at 12 months interview (D10)	166
Information about Residents 18 Months After Moving In (D13)	261
Information about Residents 30 Months After Moving In (D18)	130
Information about Residents 42 Months After Moving In (D21)	0
Exclusions:	
Refusals	428
Not able to complete	100
Died	280
Moved away	163
Management questionnaires:	
Scheme Manager Questionnaire	17
Care Manager Questionnaire	18

Table 3: Response to Questionnaires, by Scheme, Ordered by Date of Opening

Scheme	Opening date	Number of units	Permanent/ care units	Resident qu'aire	Assessment qu'aire	6 month qu'aire	18 month qu'aire	30 month qu'aire
East Riding	04/06	39	30	13	23	16	6	8
West Sussex (Horsham DC)	07/06	40	39	60	75	41	19	13
Brighton & Hove	07/06	38	33	51	53	32	17	9
Peterborough	07/06	40	34	62	62	46	26	17
Havering	08/06	64	56	18	18	16	0	10
Northamptonshire	08/06	270	90	193	37	29	0	10
Enfield	11/06	48	48	44	53	35	0	6
Rotherham	04/07	35	35	11	12	5	0	0
Bradford	04/07	46	46	47	49	23	20	11
Milton Keynes	06/07	258	90	283	60	38	29	0
Wakefield	09/07	45	45	41	45	33	21	12
Darlington	10/07	42	38	44	39	32	22	18
Ealing	10/07	35	35	14	14	6	0	0
Blackburn with Darwen	11/07	48	47	62	48	24	13	–
North Yorkshire	12/07	39	38	44	42	33	24	16
Stoke-on-Trent	05/08	75	67	44	48	29	14	–
Hartlepool	08/08	242	60	86	75	0	36	–
Derbyshire	08/08	43	39	43	42	27	14	–
West Sussex (Crawley BC)	11/08	39	39	22	22	3	–	–
All schemes		1486	909	1182	817	468	261	130

Table 4: Response to Assessment and Follow-Up Questionnaires, by Scheme, Ordered by Date of Opening

Scheme	Opening date	Permanent/ care units	Number of residents	No assessment	Assessment only	Assessment & 6 month	Assessment & 18 month	Assessment & 30 month
East Riding	04/06	30	24	1	7	8	0	8
West Sussex (Horsham DC)	07/06	39	75	0	34	20	8	13
Brighton & Hove	07/06	33	53	0	21	15	8	9
Peterborough	07/06	34	62	0	16	20	9	17
Havering	08/06	56	20	2	3	6	0	9
Northamptonshire	08/06	90	196	159	10	18	0	9
Enfield	11/06	48	53	0	18	29	0	6
Rotherham	04/07	35	12	0	7	5	0	0
Bradford	04/07	46	51	2	22	8	8	11
Milton Keynes	06/07	90	285	225	21	11	28	0
Wakefield	09/07	45	50	5	14	12	8	11
Darlington	10/07	38	44	5	7	9	7	16
Ealing	10/07	35	14	0	8	6	0	0
Blackburn with Darwen	11/07	47	62	14	24	11	13	–
North Yorkshire	12/07	38	46	4	11	10	7	14
Stoke-on-Trent	05/08	67	49	1	20	14	14	–
Hartlepool	08/08	60	87	12	42	0	33	–
Derbyshire	08/08	39	43	1	15	13	14	–
West Sussex (Crawley BC)	11/08	39	22	0	19	3	–	–
All schemes		909	1248	431	319	218	157	123

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Appendix A: Project outlines

The following project outlines can be viewed on the evaluation webpage:
http://www.pssru.ac.uk/projects/echi.htm

- Evaluation of Extra Care Housing Initiative (PSSRU Project Outline 58d, September 2006) [pdf, 55KB]

- Benchmarking Extra Care Housing for Older People (PSSRU Project Outline 61, June 2005) [pdf, 50KB]

- Older People's Perceptions of Control: The Impact of Services and Service Settings in Long-Term Care (PSSRU Project Outline 63, November 2005) [pdf, 47KB]

- Social Well-Being in Extra Care Housing (PSSRU Project Outline 66, May 2007) [pdf, 53KB]

- Evaluation of the Rowanberries Extra Care Housing Scheme in Bradford (PSSRU Project Outline 71, October 2007) [pdf, 45KB]

- EVOLVE (PSSRU Project Outline 72, with Sheffield University, January 2008) [pdf, 98KB]

- An Evaluation of the New Pocklington Place, Chatham Road, Birmingham (PSSRU Project Outline 86, June 2009) [pdf, 46KB]

- Evaluation of Extra Care at Pocklington Rise, 2009-11 (PSSRU Project Outline 87, July 2009) [pdf, 46KB]

EXTRA CARE HOUSING EVALUATION

JOB DESCRIPTION

LOCAL FIELDWORKERS

THE RESEARCH

The Personal Social Services Research Unit (PSSRU) is a Department of Health funded research centre with a long history of research in the field of care homes for older people. We have developed a programme of research on Housing with Care to investigate alternative settings to care homes, their characteristics and how they affect older people in need of care and support.

As part of the programme we are evaluating the Extra Care Housing Initiative. £87 million was made available by the government to local authority social services departments and housing associations to create up to 1,500 extra care housing places over 2004–06 and a further £60 million was allocated for places over 2006–08.

Extra care housing aims to promote independent living. People have private housing - which might be in a block of flats, a group of bungalows or a small village - with meals, domestic support, leisure and recreation facilities provided. Support and care are available 24 hours a day. The housing might be owned, rented, part owned or leasehold.

To date, we have conducted an analysis of the scheme proposals to identify their background and proposed aims, philosophy and characteristics, and held meetings with the providers of the schemes.

THE POSTS

The posts are being funded as part of the national Evaluation of the Extra Care Housing Initiative. We are recruiting people who live within a sensible travelling distance of the extra care housing scheme in their authority.

Local fieldworkers will be expected to establish a good relationship with the staff and residents of their local scheme and act as a liaison between the scheme and the researchers at the PSSRU. Local fieldworkers will be involved in the organisation of data collection in their scheme and may be asked to assist some residents to fill in self-completion questionnaires.

The position will mostly involve flexible, irregular working hours because the data collection for the research will come in waves. However, as the local point of contact

for the evaluation, post-holders will need to be available to deal with queries and administrative tasks as and when necessary.

MAIN DUTIES & RESPONSIBILITIES

- Form a friendly working relationship with the scheme manager, staff and residents.
- Be the first point of contact when staff or residents have queries about the research.
- Keep in regular contact with either the research staff at the PSSRU or a regional research advisor who will act as a supervisor to researchers in your region of the country.
- Assist in the organisation and administration of data collection.
- Assist residents with filling in self-completion questionnaires and conduct interviews on occasion.

PERSON SPECIFICATION

	Essential	Desirable	Tested at Interview
Qualifications:			
No set qualifications required.			
Experience:			
Working with older people.	✓		✓
Assisting in research		✓	
Knowledge:			
Housing and care issues affecting older people.		✓	✓
Skills:			
Excellent communication and interpersonal skills	✓		✓
Excellent organisational skills	✓		✓
Ability to work independently and manage your time efficiently	✓		✓
Additional Attributes:			
Desire to work with older people	✓		✓
Respect for resident confidentiality	✓		✓
Interest in housing and care issues	✓		✓
Time and flexibility to work within the research timetable	✓		✓

FURTHER ENQUIRIES

For further information about the post, please contact Lisa Callaghan (L.A.Callaghan@kent.ac.uk; 01227 827891); Theresia Bäumker (T.L.Baumker@kent.ac.uk; 01227 824022); Lesley Cox (L.A.Cox@kent.ac.uk; 01227

823963), Ann Netten (A.P.Netten@kent.ac.uk; 01227 823644) or Jane Dennett (J.Dennett@kent.ac.uk; 01227 827672)

BRIEF STATEMENT ON TERMS AND CONDITIONS OF EMPLOYMENT

Location: The majority of your time will spent at the extra care housing scheme being evaluated in your area. On occasion you may be required to travel to London for training or meetings.

Criminal Records Bureau (CRB) disclosure check: Please note that this post will require a CRB disclosure check. Receipt of a satisfactory check would be a condition of appointment.

EQUAL OPPORTUNITIES STATEMENT

Our Equality and Diversity Policy states: "The University of Kent is committed to the creation and support of a balanced, inclusive and diverse community which is open and accessible to all students, staff and visitors and members of the public". The full policy includes our Race Equal Policy and is available at www.kent.ac.uk/personnel/equal/eqdivpol.pdf.

Ethnicity: We would welcome applicants from minority ethnic groups, who are currently under-represented in the University.

Disability: The University is committed to the Double Tick Disability Process and guarantees an interview to people with disabilities who meet the minimum requirements (essential criteria) for a job vacancy. The Personnel Office will monitor compliance with this commitment. Please let Personnel know if any adjustments or support are required for interview, or whether any adjustments or adaptations may help you overcome operational difficulties presented by the job**.**

APPLICATIONS

Applications in writing please, to Lesley Cox (L.A.Cox@kent.ac.uk) together with a current C.V. and contact details for two referees.

Appendix C: Local interviewer training

All local interviewers were required to undergo an enhanced CRB check, and attend comprehensive training with a member of the research team. At the training, interviewers received a 'Resource Pack' including copies of all questionnaires, consent forms and information leaflets, along with guidance materials. These are reproduced in the following pages.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

RESEARCHER SAFETY WHEN CONDUCTING FIELDWORK – GUIDELINES

INTRODUCTION AND SCOPE
These guidelines are for research project managers and research officers working the field of health and social care. They aim to promote the personal safety of researchers conducting research interviews, observation or other data collection off campus, with a particular focus on lone working in private settings. The Social Research Association defines the dimensions of risk social researchers may face as:

- Increased exposure to risks of everyday life and social interaction
- Risk of being in a compromising situation, in which there might be accusations of improper behaviour
- Risk of physical threat or abuse
- Risk of psychological trauma
- Risk of causing psychological, or physical harm to others.

Protecting staff safety in the field is of critical importance, and an aspect of proper research governance. Employers have a 'duty of care' towards their employees, and have a responsibility to identify hazards at work, assess the risks, and put measures in place to avoid or control those risks. As part of this it is important that they ensure employees are aware of what actions they should take to avoid or handle threats to their safety.

PLANNING FOR SAFETY
Research project leads/grant-holders/line managers should consider researcher safety when planning and submitting proposals. This might involve:

1. Budgeting (for safety-related resources such as staffing a fieldwork contact point, taxis, appropriate overnight accommodation);
2. Design considerations (review necessity of lone interviewing, or home interviews, fieldwork time-of-day/whether evening visits avoidable, the experience, gender or ethnicity of interviewers, training in handling risk situations or unpredictable behaviour);
3. Consent and confidentiality issues (consent forms and project literature might need to be clear about legal frameworks and the potential need to disclose or report information provided within otherwise confidential interviews, or witnessed in research settings, such as allegations or suspicion of abuse).

When projects commence, research teams should discuss safety issues and how researchers might respond to any anticipated threats or sources of danger particular to the research setting or situation.

All staff carrying out research in the field should have Criminal Records Bureau (CRB) Police checks, where this will involve working with children or contact with vulnerable adults (aged 18 or over), in line with the CRB policy and guidelines (www.crb.gov.uk). (See also \\pssrusrv3\s2projects\projects\Staff Safety\PSSRU_Guidelines\CRB Policy & Guidelines.doc.)

CONTACT SYSTEM AND SUPPORT

Research Offices should give their itinerary (time, date and address) to a designated office-based colleague, and let them know when they have safely returned to the office, home or overnight accommodation. If the designated person has not been contacted on schedule they will attempt to call the researcher. Research managers should ensure that the designated person is aware of what action to take if no contact is made (particularly during evening fieldwork and overnight stays).

Line managers should ensure that they are available to researchers for debriefing/discussion if necessary to help them deal with any ethical issues/dilemmas or traumatic incidents or accounts.

EMERGENCIES AND INCIDENTS

- Incident reporting: Any incidents, including the threat of violence or verbal abuse, should be reported either to a line manager or other responsible person. Actual or attempted assault should be reported to the police as soon as possible.
- Emergency communication: Issues that might be discussed within research teams in relation to lone interviewing in people's homes might include the need for emergency communication. A 'code phrase' could be agreed with the contact person in the office to raise alarm immediately (while pretending to cancel their next appointment).
- Accidents: all accidents and near misses should be reported and investigated as soon as possible.
- Line managers should ensure that systems are in place to process, address or learn lessons from any errors, or complaints brought against staff.

FIELDWORK

- Where fieldwork visits are made within a setting where there is the opportunity to sign in and out, researchers must always do so.
- Researchers should ensure that they have a working mobile phone (and check their mobile reception is working). They should discuss the need for any particular safety equipment, such as a personal alarm, with their line manager.
- Researchers should always carry and show their PSSRU identification card showing their name and work address and telephone number.
- Researchers should carry enough money for both expected, and unexpected expenses, such as taxis.
- When interviewing in private settings, such as someone's home, researchers should:
  - let the interviewee know that they have a schedule and that others know where they are;
  - avoid divulging personal information, such as their home address;
  - sit close to a door allowing rapid exit, should this become necessary;
  - leave if at any point they feel uncomfortable or threatened.

SAFE TRANSPORT AND ACCOMMODATION

All researchers using their own cars must ensure that the terms of their motor policy have been extended to include business use. The cost of this is included in the University mileage rate.

Overnight stays should always be booked in accommodation that is suitable and safe (safe area, lock on door, secure windows). If it does not feel safe, change it.

It is useful to have a list of local licensed taxi companies.

INSURANCE

Researchers, including postgraduate students are covered by the University's insurance policies in respect of the following three circumstances:

- Business travel - losses including damage to personal/University property and harm arising from personal injury when undertaking any business trip to a place outside the UK or a trip inside the UK if the journey is by air, or the trip involves one or more overnight stays (the exact terms of this cover may change from time to time and researchers should consult the intranet insurance website before undertaking the journey);
- Public liability – harm caused to a member of the public arising from any negligent act of the researcher;
- Professional liability – harm suffered by a research subject arising from any wrongful application of the researcher's professional expertise (subject to a £10,000 excess).

- In addition, the University is insured against claims made by its employees who allege they suffered harm when carrying out their duties that arose from the negligence of the University.

- Researchers who carry out day-trips to field locations that do not fall within the University's business travel cover may wish to consider taking out personal accident cover to top up any such cover provided by their motor insurance policy.

FURTHER INFORMATION (which includes additional practical safety tips)

Association of University Teachers (1996) Personal guidelines for staff conducting interviews off campus, Circular LA/5674, AUT, London.

Craig, G, Corden, A and Thornton, P (2000) Safety in Social Research, *Social Research Update*, 29.

Paterson, B L, Gregory, D and Thorne, S (1999) A Protocol for Researcher Safety, *Qualitative Health Research*, 9, 259-269.

Social Research Association (n.d.) *A Code of Practice for the Safety of Social Researchers*, Social Research Association. http://www.the-sra.org.uk/staying_safe.htm.

Social Research Association (n.d.) *Ethical Guidelines*, Social Research Association.

The Suzy Lamplugh Trust provides advice and training. See especially http://www.suzylamplugh.org/tips/index.shtml

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

LOCAL RESEARCHERS: ROLE AND RESPONSIBILITIES

The following points outline the anticipated role and responsibilities of the local researchers. The list is not meant to be exhaustive or prescriptive at this stage but should provide a reasonably accurate description of the position in the schemes' first year of opening. We expect this list to evolve with the evaluation.

Stage 1:   Make contact with the scheme manager and build relationships with the staff and residents.

This is going to be a crucial part of the job and it will be up to the local researcher to work out the best way to establish good relationships in their scheme. We would suggest: meeting the scheme manager and being introduced to staff, speaking at early residents' meetings and being available at certain times in the first few weeks to talk to people about the research. Whilst it is vital to build up good relationships with the staff team, it will be important that residents see you as separate from them and feel assured that anything they disclose to you will only be passed on to the team at PSSRU.

We will also want you to use the 'moving-in' period to compile a list of residents living in the scheme, which can be updated over time as people leave and new people arrive. An excel spreadsheet will be provided for this purpose.

Stage 2:   Ensure you have a good understanding of the research material and data collection process in your scheme.

As the first point of contact for the research, it is essential that you have a sound understanding of the information we are collecting (both about and from residents) and are familiar with the questionnaires. Training will be provided, but you will also need to take responsibility for ensuring you are very familiar with the questions and the research material.

Stage 3:   Understand the routes by which people move into the scheme and use this knowledge to benefit the research.

We will require you to collect the assessment questionnaires about residents (or the information to complete the forms yourself) from either the scheme manager or a social services contact (this will vary by scheme) and so understanding the routes by which people move into the scheme is going to be important in helping you chase this information on our behalf. We would also expect you to use your local knowledge to advise the research team at the PSSRU if the data collection processes in place are not working or could be improved.

Stage 4:   Obtain consent from residents to collect assessment information.

In some cases, the consent leaflet for obtaining assessment information will be handed round and collected by the scheme staff, but in other cases the local researcher will be responsible for this. You will need to ensure that residents are clear about what they are being asked to give consent for, and reassure them if they have any concerns.

Stage 5: Liaise with manager and SS to obtain assessment information on residents, check questionnaires from managers for missing or incomplete information and chase this information on our behalf.

In some cases, the scheme manager will fill in the SS assessment on residents, in other cases the SS assessment team will complete this and the information will not be available at the scheme itself. It will be your responsibility to chase this information and make sure that it is completed. Also when you collect the questionnaires containing information about residents from the scheme manager or social services contact, you will need to check that the information is complete and chase incomplete or missing information. It may be that you will be responsible for transferring assessment information onto our questionnaire from information held by the scheme or SS. We will arrange a secure method of returning these questionnaires to the PSSRU with you nearer the time.

Stage 6: Explain the research to residents, hand out the questionnaires and assist in questionnaire completion where required.

Once the scheme is more or less full and has been operational for about one month, we will want residents to begin to fill in self-completion questionnaires about their experiences of the move and their expectations for the future. These questionnaires are likely to be handed out and completed in the second or third month of opening for most schemes. It is important that the information is relatively fresh in people's minds and that they are still new to the scheme. How you introduce this questionnaire to residents and ask them to fill it in and return it to you will be your choice, as you will be best placed to make these sorts of decisions.

The last page of this questionnaire includes a sentence asking residents if they are happy for us to combine their responses on the questionnaire with their assessment information. It may be that you will need to explain this further to residents and answer any concerns that they may have.

Stage 7: Collect the questionnaires from residents and encourage people to fill them in and record your progress.

Once again this will be a trial-and-error process and we will expect you to take the lead on how best to organise this in your particular scheme. We want to receive as many resident questionnaires as possible and so part of your job will be to collect these in before returning them to us. In some cases you will assist in completing the questionnaire and so can collect those in immediately; others could be collected at the start/end of a residents' meeting. Any outstanding questionnaires could be followed up by knocking on doors and speaking to people to see if they need help filling it in or simply to see whether they have decided to opt out of that part of the study. You must record your progress on the excel spreadsheet provided.

Stage 8: Maintain regular contact with the scheme manager about new residents moving into the scheme and existing residents leaving or passing away.

After the initial moving-in period when residents move in en masse, individuals will leave the scheme or pass away and new people will move in to replace them. We need questionnaires to be completed about these people and so you will need to keep on top of the comings and goings in the scheme and ensure the relevant information is collected for each person. We suggest attending a monthly residents' meeting (or a suitable equivalent) and using this visit to also speak to the manager about changes in the scheme and data we need them to collect.

Stage 9: Maintain regular contact with the PSSRU.

Keep us informed of your progress and liase with us if you have any problems.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

INTERVIEWING TECHNIQUES

Below is some advice adapted from a recent training course in interviewing held at the PSSRU, run by Liz Spencer and Pamela Campanelli of Q2 Training Complete.[1]

Questionnaire interviewer's tasks are to:
- Gain the participant's cooperation
- Accurately ask questions and record answers
- And, whether interviewers know it or not, they educate the participant as to the participant's role
  - Participants may not understand what is required of them – for example, whether we want a long, in-depth answer to a question ('open questions) or their choice from a number of options ('closed questions')
  - It may be helpful for you to describe at the beginning of the interview the type of questions involved. Most of the interviews in this project involve mainly closed questions, with a few open questions along the way.
  - So, before the interview, you may like to say something like this:

"You will be asked two kinds of questions in this [interview]. In some cases, I will be asking you to answer questions in your own words.

For other questions, you will be given a set of answers, and you will be asked to choose one that is closest to your own view. Even though none of the answers may fit your ideas exactly, choosing the response closest to your views will enable us to compare your answers more easily with those of other people."[2]

The following points are some general pointers to bear in mind when carrying out interviews, adapted from a different source, D.A. de Vaus (1985), *Surveys in Social Research (3rd edn.)*. Some of them may seem fairly obvious, but you may find them helpful.

1. Promote a relaxed atmosphere in which the respondent can concentrate; we would advise that interviews take place in the respondents' home.

2. Try to discourage the presence of third parties, unless the respondent feels strongly that they would like someone else there.

3. If a third party is present, discourage them from offering their opinions by politely suggesting that their opinions would be of interest at the end of the interview.

4. An interview is not an equal exchange of information. Try to keep the respondent on track as far as possible, but avoid making the interview sound like a test.

5. To discourage respondents from giving answers that they think the interviewer might want, it is important to avoid giving the interviewee any idea of your opinions. Avoid showing anger or surprise. If they ask for your views, deflect the question at least until the end of the interview, saying that it is best to wait until then.

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[1] www.q2trainingcomplete.co.uk
[2] Taken from Fowler, F. J. Jr. (2002). *Survey Research Method,* 3rd edn., Thousand Oaks, CA: Sage. p130.

6. When a person seems to provide an answer to a later question in response to an earlier question, still ask the later question. Since question order can affect responses it is important that all interviewees answer the questions in the same order. In such situations, the apparently redundant question might be prefaced by saying 'I'd just like to check...'

7. Because uniformity is important, questions should be read exactly as they appear on the questionnaire.

8. Rather than relying on memory, answers should be recorded as they are given.

9. The questionnaire should be checked once the interview is completed to ensure that no questions have been missed.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

SHOW CARDS

We have produced some yellow show cards, which will help you obtain a response from the residents during some of the interviews (6-month and 18-month follow-up; 12-month social well-being interview). Some of the questions have several possible answers, and from past experience, interviewees generally find it helpful to have these different possible answers displayed in front of them. Instructions for when to use the show cards are clearly highlight in yellow on the questionnaire' for example:

9a   Do you receive home care?
        ☐Yes
        ☐No   ☐Resident   ☐Staff
        ☐Don't know

        If yes, how many hours per week? ☐☐☐
        ☐Don't know

        If the respondent does not know how many hours, please ask them to choose one of the following bands (show card 3):
        ☐ 1–5 hours a week
        ☐ 6–10 hours a week
        ☐ 11–15 hours a week
        ☐ 16–20 hours a week
        ☐ 21 hours a week or more

Some residents will find the show cards useful, but some will prefer to simply have the options read out to them by you. In general, the interview progresses more quickly if residents are willing to use the show cards, as it tends to keep their answers on track. Therefore we suggest that you show them a show card at the beginning of the interview and explain to them that it is helpful **to us** in that it maintains consistency in their answers, and means you as the interviewer don't have to do as much talking! However, you should give them the choice as to whether they are used or not.

<h1 style="text-align:center">EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE</h1>

<h2 style="text-align:center">INFORMATION ABOUT DEALING WITH COMPLAINTS/ CONCERNS</h2>

MAJOR CONCERNS

During an interview, a resident may raise something which gives you serious cause for concern about their well-being. For example, you may suspect that some form of abuse has occurred/is occurring, or that there is serious cause for concern about their health and well-being which is not being picked up by staff at the scheme.

If this does occur, please give us a ring to make us aware of the situation and discuss any further steps to take. A particular issue here is that, when they agree to take part in the research, participants are assured of confidentiality; i.e. what they tell us will not be disclosed to any third parties (such as staff at the scheme). However, this needs to be balanced against our duty of care towards the participants in our study.

MINOR CONCERNS

There may also be issues raised by a resident which are not so serious, but nonetheless cause you some concern. For example, the resident may have complaints about the care that they are receiving.

The issue here is that many people don't like to make a complaint, as they don't want to be a nuisance or they feel that there may be negative consequences for them if they do complain. In these situations, please encourage the resident to go through the complaints procedures in place in their scheme (it may be that you need to make yourself aware of what these are).

Of course, the differences between 'major' and 'minor' concerns are not always clear-cut; if in doubt please get in touch with us.

FEEDING BACK PROBLEMS TO THE SCHEMES

As well as the more formal data (e.g. the 'tick box' answers to questions on the questionnaires) we will ensure we pick up the comments made by residents (generally at the end of the yellow 'Moving In' questionnaire, or the 6-month and 18-month follow-ups) and feed these comments back to schemes and the Department of Health in a useful way.

So that residents' confidentiality is protected, we plan to feedback the comments made by residents (particularly when problems are raised) to the schemes on a general level. We won't say to an individual scheme that a particular problem has been mentioned as occurring in their scheme, unless it is of major concern (e.g. abuse).

If there are any other general problems that you have picked up on that you think would be useful for us to know, please mention these when you send your spreadsheet to Theresia on a monthly basis.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

EXPLANATION OF QUESTIONNAIRES FOR THE MAIN EVALUATION

The table below provides a brief explanation of each questionnaire. The time frame suggested is only approximate and will vary across schemes depending on when scheme managers are willing for you to approach residents / involve yourself at the scheme. Please bear in mind however, that we would like to obtain data that is reflective of the time at which it should have been collected (e.g. admission/ 6-months etc), and that for those questionnaires where it is necessary to approach the resident, the sooner it is completed the better their recall ability will be.

PLANNED ACTIVITY	METHOD	TIME-FRAME
1) Inform the residents of the PSSRU's research study at their scheme, and invite them to take part	**Information Sheet** (Yellow A4) For residents to keep, show to their relatives /carers. *Note:* - *Introduce yourself / the research to residents at residents' meetings, coffee mornings, social activities etc.*	**At Admission** Within first 2 months of opening, with consent of scheme manager.
2) Obtain the residents consent; i.e. ask them to allow the information from their care assessment to be shared with the PSSRU	**Consent Booklet** (White A5) Provide resident with Information Sheet of above (1), if not given to them previously. *Note:* - *This consent refers to the Assessment Questionnaires (3).*	**At Admission** Within first 2 months of opening.
3) Collect information about the key characteristics of the residents: - e.g. demographic, previous accommodation, ADLs, service use information	**Assessment Questionnaire** (White A4 4-page) Data to be obtained from admission/ assessment data records kept by the scheme. *Note:* - *Ideally, residents should not be involved in this process. However, some local fieldworkers have found it necessary to approach residents to obtain some missing data not available from any other sources.* - *If the answer is 'don't know', please ensure that the relevant box is ticked.*	**At Admission** Complete within first 2-4 months of opening if possible.

4)	Ask residents about their reasons for and experiences of moving, their expectations and views.	**Resident (Self-completion) Questionnaire** **'Moving into the scheme'** (Yellow A4 8-page) Residents can complete these on their own, or if they are unable to do so, you will need to assist them. This should be at a time/place of their choosing; e.g. communal area or their flats etc. *Note:* - *Questionnaire is a self-completion document, so the decision to complete it (and sign name) will be treated as giving consent.* - *On last page, obtain consent for linking this data with that of (3) Assessment Qu.*	**At Admission** Complete within first 2-4 months of opening if possible.
5)	Collect follow-up information to that obtained in Admission Questionnaire at admission (3).	**6 Month Assessment Questionnaire** (White A4 12-page) This is to be completed by means of an *interview* you will conduct with the resident at a time/place of their choosing. *Note:* - *It is important to use the wording provided in the questionnaire, as this will ensure that across schemes, there is a consistency in the data obtained.* - *If resident prefers, use show cards where the different possible answers are displayed in front of them.*	**At 6 Months** Complete within first 2-4 months after 6-month stage.
6)	Lisa will interview a small sample of residents about the social life at the scheme. She may ask you for help in selecting participants and setting up interviews.	**Social Well-Being Information sheet** (Green A4) For residents to keep, show to their relatives / carers **Invitation to Interview Letter** (Green A4) For those residents who we plan to invite to take part in an interview	**At 6 approximately Months** Lisa will liaise with you about this

7)	Ask residents about their experiences of the social life at the scheme, their relationships and well-being	**Resident (Self-completion) Questionnaire** **'Living at the scheme'** (Green A4 16-page) Residents can complete these on their own, or if they are unable to do so, you will need to assist them. This should be at a time/place of their choosing; e.g. communal area or their flats etc. *Note:* - *Questionnaire is a self-completion document, so the decision to complete it (and sign name) will be treated as giving consent.* - *On p15, there is a box for residents to tick indicating their interest in completing a follow-up interview (see 7 below)*	**At 12 Months** Complete within first 2-4 months after 12-month stage
8)	Ask a sample of residents (up to 10, or 30 in the villages) in more depth about their experiences of the social life at the scheme, their relationships and well-being, and any care and support they may receive.	**Resident Interview at 12 months** (White A4 32-page) This is an interview to complete with the resident at a time/place of their choosing. It follows up on some of the issues in the previous resident questionnaire. *Note:* - *It is important to use the wording provided in the questionnaire, as this will ensure that across schemes, there is a consistency in the data obtained.* - *If resident prefers, use show cards where the different possible answers are displayed in front of them.*	**At approx. 12 Months** Complete within first 2-4 months after 12-month stage, following previous resident questionnaire.
9)	Collect follow-up information to that obtained in Admission Questionnaire at admission (3), and the Six Month Assessment (5).	**18 Month Assessment Questionnaire** Again, this is to be completed by means of an *interview* you will conduct with the resident at a time/place of their choosing. It is very similar to the questionnaire used at six months.	**At 18 Months** Complete within first 2-4 months after 18-month stage.

10) Collect follow-up information to that obtained in (3), (5) and (9).	**30 Month Assessment Questionnaire** Again, this is to be completed by means of an *interview* you will conduct with the resident at a time/place of their choosing. It is very similar to the questionnaire used at six and eighteen months.	**At 30 Months** Complete within first 2-4 months after 30-month stage.
11) Collect follow-up information to that obtained in (3), (5), (9) and (10).	**42 Month Assessment Questionnaire** Again, this is to be completed by means of an *interview* you will conduct with the resident at a time/place of their choosing. It is very similar to the questionnaire used at six, eighteen and thirty months.	**At 42 Months** Complete within first 2-4 months after 42-month stage.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE
INFORMATION ABOUT RESIDENTS 6 MONTHS AFTER MOVING IN

As you may be aware, we have had some discussions about the best method by which to obtain information about resident's health at 6 months after opening. As a result, and with the help of feedback from some of you, we have amended our original questionnaire and hope that the enclosed is a workable solution. Much of the information will now be gained directly from the residents, rather than records held by the schemes.

As outlined on the front of the questionnaire, there are 4 sections:

- **Section A** has four brief questions for you to complete about the resident.

- **Section B** consists of some of the questions from the original assessment questionnaire, but written in an interview format so that they are easier to complete with the resident. There are also some additional questions on well-being.

- **Section C** consists of further questions from the original assessment questionnaire, again written in an interview format, along with questions about services received by the resident. Residents may be unable to answer some of the questions in this section, in which case we would like you to ask them of the scheme manager, care manager or other appropriate member of staff, subject of course to the resident's consent. In this section, please also tick the relevant box after each question to indicate whether the information was gained from the residents, or from a member of staff.

- **Section D** is an interview for you to conduct with the scheme manager, care manager or other appropriate member of staff about the resident, again subject to their consent. This section consists of those questions which cannot easily be asked of residents themselves such as on cognitive impairment. It is particularly important that the questions about cognitive impairment are asked of a member of staff who is suitably qualified to make such judgements. Although we realise that many of you have had experience with people with cognitive impairments etc., and may be able to make judgements about their level of ability, it is important for the reliability and consistency of our research that this kind of information is gained from staff/records. If it is impossible to gain the information from staff/records, and you do fill it in yourself, please record that you have done so on the form.

IMPORTANT: When interviewing the residents or staff, please use the wording provided in the questionnaire. Although we understand that the residents' answers might tend to digress from the main point, we would ask you to please minimise any discussion and follow the interview schedule as closely as possible. This will help to ensure that, across schemes, there is a consistency in the data obtained, and the effects of any interviewer intervention is minimised.

WELL-BEING' SECTION OF THE SIX-MONTH ASSESSMENT QUESTIONNAIRE

Some of the questions in this section may seem intrusive and difficult to ask. However, this is in general the nature of scales measuring people's well-being; in order to get the full picture, it is best to ask about both the positive and negatives aspects of a person's life.

Please be assured that the last thing we want to do is to cause people unnecessary distress. These questions are part of a scale called the CASP-19, developed as part of the Growing Older Programme (http://www.growingolder.group.shef.ac.uk/) specifically for use with older people. Although the scale was originally designed for people in younger old age, it has been used in a variety of studies with people from aged 50 to over 85. (e.g. The English Longitudinal Study of Aging (http://www.ifs.org.uk/elsa/index.php) and the evaluation of Berryhill Retirement Village, 'New lifestyles in old age'; Bernard, Bartlam, Biggs & Sim, 2004).

Nonetheless, there is the risk that some questions may upset participants. These questions should be asked sensitively and keeping an eye-out for distress. If a participant does show signs of distress, if necessary please stop this part of the interview (recording that you have done so on the form). However, please bear in mind that distress can indicate that the questions are 'working' – as mentioned above, it is just as important to find out if a person is unhappy as it is to find out they are happy. It is also worth noting that, in some cases, it may be that the question causes more distress and discomfort to the *interviewer* than to the respondent.

We have added in the following statement to the questionnaire to read out before asking the well-being questions, which will hopefully help to reassure participants:

'The next section is about your well-being and quality of life. There will be a list of statements. Some of the statements might seem slightly odd to you, but they are part of a list of statements that different people have used to describe their lives or how they feel. For example, there are some statements about how people feel about their life, about their health, and about the future.

I am going to read out each statement, and ask you to say how much you agree with each one, in terms of the options on this card (show card 2).'

Please take time to familiarise yourselves with this new questionnaire, and do not hesitate to get in touch with us if you have any queries:

Lisa: L.A.Callaghan@kent.ac.uk   01227 827891
Theresia: T.L.Baumker@kent.ac.uk   01227 824022

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

12-MONTH RESIDENTS' QUESTIONNAIRE: LIVING AT THE SCHEME

INSTRUCTIONS FOR LOCAL RESEARCHERS

This questionnaire is part of the work we are doing within the evaluation on social well-being. It is designed to follow up on some of the topics covered in the first residents' questionnaire on experiences and expectations of moving to extra care, as well as finding out more about residents' social lives.

The questionnaire should be given to <u>all</u> residents who still wish to take part in the research. We expect that most residents will need support in completing this new questionnaire, in the same way as with the first residents' questionnaire. If there are any residents with a cognitive impairment, who are unable to take part themselves, feel free to ask a relative if they would like to act as a proxy and complete the questionnaire on behalf of the resident (I can send you a different version of the questionnaire for this purpose).

Various topics are covered:

Q1-3	The resident's feelings about their social life
Q4-6	How often they take part in and activity or group, what sort of activities or groups they take part in, how many activities or groups they take part in

Note: This question refers to activities and groups held both at the scheme, and elsewhere (e.g. out in the local community, at a day centre, at a church etc.)

Q7	Whereabouts their social life is located
Q8	How easy they find it to access places in their local area
Q9	Obstacles to taking part in activities/groups
Q10	Facility use

Note: We realise that not all facilities listed will be present in every scheme. So, for this question, please put a line though any facilities that are not present at the scheme.

Q11-12	Feelings towards people from the community coming in to use facilities
Q13-15	Who would they turn to for advice, help and support?
Q16-19	Friends
Q20-21	Family
Q22-25	Health
Q26-27	Quality of life
Q28	Control over daily life
Q29	Where is home?
Q30	How well they feel their home meets their needs
Q31	Has the scheme met their expectations?
Q32	Did they have help filling in the questionnaire?

Then, there is a paragraph asking the resident whether they are happy for us to link their responses in this questionnaire with the information previously gathered as part of the evaluation.

The questionnaire ends with a paragraph inviting the resident to take part in a follow-up interview on some of the topics covered in the questionnaire, but in more depth. We would hope that about 10 people from each scheme will agree to take part in this interview. I will come to the scheme for a day

to do 2 or 3 of the interviews, brief you on the interview and answer any questions, and then you would carry out the rest of the interviews at times convenient to yourself.

Please get in touch if you have any questions. Once you have completed a few of the questionnaires with residents, feedback on how easy they were to complete and whether residents understood the content would be much appreciated.

EVALUATION OF THE EXTRA CARE HOUSING INITIATIVE

12-MONTH RESIDENTS' INTERVIEW

INSTRUCTIONS FOR LOCAL RESEARCHERS

This interview is part of the work we are doing within the evaluation on social well-being. It is a follow-up to the 12-month survey about living at the scheme. At the end of the survey, residents are given the option of taking part in a follow-up interview; we hope to interview 10 residents per scheme (30 in each of the villages).

The interview is structured, in that there are questions with specific answers to chose from, but we have also tried to incorporate some more open-ended questions. We have tried to give interviewer guidance throughout the interview so that it is clear how questions should be asked and completed. Please make yourself familiar with the interview schedule beforehand, as some questions do have a bit of a complicated structure.

Show cards
Feedback from some of our local fieldworkers indicates that residents generally choose not to use the show cards if given the option. In some cases, residents have been quite offended at the thought of needing to use show cards, and have felt patronised. However, for this interview, I have found that using show cards *considerably* speeds up the interview, as the interviewer does not have to read out each different response (of which there are many). When asking residents whether they would like to use show cards, it may be helpful to emphasise that using them will mean that the interview will take less time, and that using shows cards actually help the *interviewer* because we don't have to do so much talking!

Timing
The interview should take between 45 minutes and an hour. However, we have found that some of the questions are quite difficult to answer immediately, and that residents like to talk about the issues involved. Of course, any information they give us is interesting and valuable, but the main purpose of this particular interview is to get answers to specific questions, to complement the more open-ended interviews I carried out at 6 months. With this in mind, the following are some phrases I was given to use when you need to return to the question when a resident is talking too much around the issue – you may (or may not!) find them useful too:

- 'That's really interesting, so thinking about what you've just said, which option do you think is best for you….'
- 'I'm sorry to interrupt because what you are saying is very relevant to the question, but I am aware that we only have a certain amount of time and we have so many more questions to get through….'
- 'Actually, before you say anymore, perhaps we should look at the next question, it's very relevant to what you were talking about' (*only if it is of course*!)

Structure of the interview:

Questions 1-6 are basic background to establish consent, and whether the participant receives paid help, care or support at the scheme.

Section A covers some basic background information, which it is important to get when no assessment information is held on the interviewee.

Section B is about the resident's social life, focusing on what activities they take part in inside and outside of the scheme, how much they enjoyed those activities, and what they feel they get out of the activities that they do.

Section C is about living at the scheme, with questions on daily life (meals etc.), and scheme life in general.

Q32: This question consists of a set of statements taken from a scale designed by Moos & Lemke (1996) to measure to social climate of sheltered care facilities. Some of the statements are a bit unclear, so I have added in some notes to the questionnaire about what they are supposed to measure. Additional guidelines for this question (from Moos & Lemke, 1996) are as follows:

- Respondents may say that they cannot answer 'yes' or 'no' to a statement because it is 'sometimes true and sometimes false'. Tell them to answer in terms of what generally is the case. If it is *mostly* true, circle yes; if it is *mostly* false, circle no.
- Respondents may say that the question is inappropriate for their scheme. In such cases, the statement should generally be marked 'no'. At other times, this response indicates that the statement is awkward or embarrassing for the person to answer. Point out that for some schemes the question can be answered yes and for others it can be answered no; try to persuade the respondent to answer the question.
- The respondent may ask what a question means. Try to explain as clearly as you can while staying close to the wording and tone of the original statement.

Section D is about any links the resident may have with their local community.

Section E is about the resident's well being, quality of life and relationships.

Q42: This question is a repeat of the well-being scale that was used in the 6-month Assessment Questionnaire. We are asking these questionnaires again so as to pick up any changes in well-being that may have occurred in the last 6 months.

Some of the questions in this section may seem intrusive and difficult to ask. However, this is in general the nature of scales measuring people's well-being; in order to get the full picture, it is best to ask about both the positive and negatives aspects of a person's life.

Please be assured that the last thing we want to do is to cause people unnecessary distress. Nonetheless, there is the risk that some questions may upset participants. These questions should be asked sensitively and keeping an eye-out for distress. If a participant does show signs of distress, if necessary please stop this part of the interview (recording that you have done so on the form). However, please bear in mind that distress can indicate that the questions are 'working' – as mentioned above, it is just as important to find out if a person is unhappy as it is to find out they are happy. It is also worth noting that, in some cases, it may be that the question causes more distress and discomfort to the *interviewer* than to the respondent.

Q43 – Q52: These are part of the Practitioner Assessment of Network Type assessment instrument (PANT; Wenger, 1991), which is designed to discover which of 6 different types of support network the resident has (for example, whether they are family-based or locally based).

Q59: These statements make up a scale designed to measure the extent of social support the resident has.

Q61: As the interview is fairly long, Q61 asks the resident whether they are happy to continue with the interview (another 2 sections if they receive paid help, care or support, or another 1 section if they do not) or if they would prefer to end at this point. These sections are not as important for the social well-being part of the work as the rest of the interview, so it is not crucial for them to be completed.

Section F: This section is about the way the scheme building is designed, and the facilities available.

Section G: This section is about quality of any paid help, care or support services that the resident may receive at the scheme. Please note that we would like the resident to focus on help, care and support received at the present time.

Appendix D: Data collection materials

All of the files listed below are available to download as PDFs at http://www.pssru.ac.uk/extra-care-housing-evaluation/data-collection-materials/

Main evaluation

- ECHIE_LO2: Information leaflet about the evaluation
- ECHIE_DO2: Information about Residents at Assessment questionnaire
- ECHIE_DO3: 'Moving In' questionnaire
- ECHIE_DO4: Information about Residents Six Months After Moving In questionnaire
- ECHIE_DO5: Consent form relating to collection of Information about Residents at Assessment
- ECHIE_D11: Consent form relating to collection of Information about Residents Six Months After Moving In
- ECHIE_D13: Information about Residents 18 Months After Moving In questionnaire
- ECHIE_D14: Consent form relating to collection of Information about Residents 18 Months After Moving In
- ECHIE_D18: Information about Residents 30 Months After Moving In questionnaire
- ECHIE_D19: Consent form relating to collection of Information about Residents 30 Months After Moving In
- Scheme Manager Questionnaire 2009
- Care Manager Questionnaire 2009
- Local fieldworker feedback questionnaire

Social well-being project

- ECHIE_LO3: Social well-being project – information letter about the social well-being project
- ECHIE_LO4: Social well-being project – invitation to interview at six months
- ECHIE_DO6: Social well-being at six months – consent form
- ECHIE_DO7: Social well-being at six months – interview schedule for residents
- ECHIE_DO8: Social well-being at six months – interview schedule for staff
- ECHIE_DO9: Social well-being at 12 months – survey for residents
- ECHIE_D10: Social well-being at 12 months – interview schedule for residents
- ECHIE_D12: Social well-being at 12 months – consent form

Appendix E: Sources of questions/scales used in data collection instruments

1. **Information about Residents at Assessment questionnaire (D02)**

   - Measure of physical functioning: Barthel Index of Activities of Daily Living (Mahoney and Barthel, 1965) [Q.18, Q.19, Q.20]

   - Measure of cognitive functioning: Minimum Data Set Cognitive Performance Scale (MDS CPS) (Morris et al., 1994) [Q.18, Q.23, Q.25, Q.26]

2. **'Moving In' questionnaire (D03)**

   - Self-perceived general health – single question (WHO-Europe, 1996; Robine et al., 2002) [Page 7, Q.1]

3. **Information About Residents Six Months After Moving In questionnaire (D04)**

   - CASP-19 scale to measure quality of life/well-being (Hyde et al., 2003) [Q.8]

   - Measure of physical functioning: Barthel Index of Activities of Daily Living (Mahoney and Barthel, 1965) [Q.5, Q.17, Q.18]

   - Measure of cognitive functioning: Minimum Data Set Cognitive Performance Scale (MDS CPS) (Morris et al., 1994) [Q.5, Q.20, Q.22, Q.23]

4. **Information About Residents 18 Months, 30 Months and 42 Months After Moving In questionnaires (D13, D18, D21)**

   - Similar to Six Months After Moving In questionnaire (D04)

5. **Social Well-Being at 12 Months – questionnaire (D09)**

   - Global quality of life – single question (Bowling, 1995) [Q.26]

   - Self-perceived general health – single question (WHO-Europe, 1996; Robine et al., 2002) [Q.22]

   - Four 'outcomes' questions taken/adapted from the 2007 version of the national Service User Experience Survey (UES). These questions have since been refined and developed as part of work on the Adult Social Care Outcome Toolkit (ASCOT – see Netten et al., 2009) [Q.1, Q.3, Q.8, Q.28]

   - One question from Hartrigg Oaks study (Croucher et al., 2003) [Q.6]

   - Two questions on contact with friends/family, adapted from ONS questions on social capital (Green and Fletcher, 2003) [Q.16, Q.20]

6. **Social Well-Being at 12 Months – interview (D10)**

- CASP-19 scale to measure quality of life/well-being (Hyde et al., 2003) [Q.42]

- The Sheltered Care Environment Scale (SCES), to measure social climate – three subscales from this: cohesion, conflict and independence (Moos and Lemke, 1996) [Q.32]

- A scale to measure cohesion/attachment to place, adapted from the questionnaire being used in Keele University's Longitudinal Study of Ageing in a Retirement Community (LARC) [Q.31]

- Practitioner Assessment of Network Type (PANT) (Wenger, 1994) [Q.43–Q.52]

- Perceived Social Support scale used in the Health Survey for England 2000 (Tait and Fuller, 2002) [Q.59]

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Tait, C. and Fuller, E. (2002) *Health Survey for England 2000: Psychosocial Well-being among Older People*. The Stationery Office, London.

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WHO-Europe (1996). *Health Interview Surveys: Towards International Harmonisation.* WHO Regional Publications, European Series, No. 58, Copenhagen.

Appendix F: Derived measures of dependency

Barthel Index of Activities of Daily Living

Reference: Mahoney, F.I. and Barthel, D.W. (1965) Functional evaluation: the Barthel Index. *Maryland State Medical Journal*, 14, 2, 61-65.

The Barthel Index is computed as the sum of the scores for the ten items shown, and ranges from 0 (highest level of dependency) to 20 (lowest level of dependency). The question numbers refer to the assessment questionnaire (D02).

Function	Score	Description	Question(s)	Code(s)
Bowels	0	Incontinent (or needs to be given enemata)	Q20	3
	1	Occasional accident (once/week)		2
	2	Continent		1
Bladder	0	Incontinent, or catheterized & unable to manage	Q19	3
	1	Occasional accident (max once per 24 hours)		2
	2	Continent (for over 7 days)		1
Grooming	0	Needs help with personal care	Q18f	3,4
	1	Independent face/hair/teeth/shaving (implements provided)		1,2
Toilet use	0	Dependent	Q18e	3,4
	1	Needs some help, but can do something alone		2
	2	Independent (on & off, dressing, wiping)		1
Feeding	0	Unable	Q18i	3,4
	1	Needs help cutting, spreading butter etc		2
	2	Independent (food provided in reach)		1
Transfer	0	Unable – no sitting balance	Q18d	4
	1	Major help (1 or 2 people, physical), can sit		3
	2	Minor help (verbal or physical)		2
	3	Independent		1
Mobility	0	Immobile	Q18c/Q21	Q18c=3 & Q21=1, Q18c=4
	1	Wheel chair independent including corners etc		Q18c=1,2 & Q21=1
	2	Walks with help of 1 person (verbal or physical)		Q18c=3 & Q21≠1
	3	Independent (but may use any aid, eg stick)		Q18c=1,2 & Q21≠1
Dressing	0	Dependent	Q18h	3,4
	1	Needs help, but can do about ½ unaided		2
	2	Independent (including buttons, zips, laces, etc)		1
Stairs	0	Unable	Q18a	4
	1	Needs help (verbal, physical, carrying aid)		3
	2	Independent up & down		1,2
Bathing	0	Dependent	Q18g	2,3,4
	1	Independent (or in shower)		1

MDS Cognitive Performance Scale

Reference: Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V. and Lipsitz, L.A. (1994) MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences*, 49, 4, M174-M182.

Equivalence Between MDS CPS Items and PSSRU Variables

MDS CPS item	Score	Description	Variable(s)	Code(s)
Comatose	0	No		
	1	Yes		
Short-term memory	0	Memory OK	Q23	2
	1	Memory problem		1
Decision making	0	Independent	Q25	1
	1	Modified independent		2
	2	Moderately independent		3
	3	Severely impaired		4
Understood	0	Understood	Q26	1
	1	Usually understood		2
	2	Sometimes understood		3
	3	Rarely/never understood		4
Eating	0	Independent	Q18i	1
	1	Supervision		2
	2	Limited assistance		
	3	Extensive assistance		3
	4	Total dependence		4

Computation of Impairment and Severe Impairment Counts for Constructing Scale

Impairment/Severe Impairment Counts	Components	Scores	Variables	Codes
Impairment count (IC)	Decision making	1,2	Q25	2,3
	Understood	1,2,3	Q26	2,3,4
	Short-term memory	1	Q23	1
Severe impairment count (SIC)	Decision making	2	Q25	3
	Understood	2,3	Q26	3,4

Decision Rules for Scoring MDS CPS Scale

Score	MDS CPS Category	Decision Rule
6	Very Severe Impairment	Comatose = 1, Comatose = 0 & Decision making = 3 & Eating = 4
5	Severe Impairment	Comatose = 0 & Decision making = 3 & Eating ≠ 4
4	Moderately Severe Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 2
3	Moderate Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 1
2	Mild Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 0
1	Borderline Intact	Comatose = 0 & Decision making ≠ 3 & IC = 1
0	Intact	Comatose = 0 & Decision making ≠ 3 & IC = 0

Decision Rules for Scoring MDS CPS Scale from PSSRU Data

Score	MDS CPS Category	Decision Rule
6	Very Severe Impairment	Q25 = 4 & Q18i = 4
5	Severe Impairment	Q25 = 4 & Q18i = 1,2,3
4	Moderately Severe Impairment	Q25 = 1,2,3 & IC ≥ 2 & SIC = 2
3	Moderate Impairment	Q25 = 1,2,3 & IC ≥ 2 & SIC = 1
2	Mild Impairment	Q25 = 1,2,3 & IC ≥ 2 & SIC = 0
1	Borderline Intact	Q25 = 1,2,3 & IC = 1
0	Intact	Q25 = 1,2,3 & IC = 0

Appendix G: Outputs

The Evaluation webpage has links to many of the outputs listed below:
http://www.pssru.ac.uk/projects/echi.htm.

Early outputs

Darton, R. and Muncer, A. (2005) Alternative housing and care arrangements: the evidence. In B. Roe and R. Beech (eds) *Intermediate and Continuing Care: Policy and Practice*. Blackwell Publishing, Oxford, 183-203.

Dawson, L., Williams, J. and Netten, A. (2006) Extra care housing: is it really an option for older people? *Housing, Care and Support*, 9, 2, 23-29.

Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A. (2008) *Evaluation of the Extra Care Housing Funding Initiative: Initial Report*. PSSRU Discussion Paper No. 2506/2, May 2008.

Callaghan, L. (2008) *Social Well-Being in Extra Care Housing: An Overview of the Literature*. PSSRU Discussion Paper No. 2528, March 2008.

Darton, R. and Callaghan, L. (2009) The role of extra care housing in supporting people with dementia: early findings from the PSSRU evaluation of extra care housing. *Journal of Care Services Management*, 3, 3, 284-294.

Main evaluation papers

Netten, A., Darton, R., Bäumker, T. and Callaghan, L. (2011) *Improving Housing with Care Choices for Older People: An Evaluation of Extra Care Housing.* Personal Social Services Research Unit, University of Kent, Canterbury, December 2011.

Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A. (2011) *The Characteristics of Residents in Extra Care Housing and Care Homes in England*. PSSRU Discussion Paper No. 2603/4, April 2011. (Published in *Health and Social Care in the Community*, 5 August 2011 (online version).)

Bäumker, T., Darton, R., Netten, A. and Holder, J. (2010) *The Development Costs and Funding of Extra Care Housing*. PSSRU Discussion Paper No. 2708/2, December 2010. (Published in *Public Money and Management*, November 2011, 31, 6, 411-418.)

Bäumker, T., Callaghan, L., Darton, R., Holder, J., Netten, A. and Towers, A. (2011) *Deciding to Move into Extra Care Housing: Residents' Views.* PSSRU Discussion Paper No. 2709/2, August 2011. (Published in *Ageing and Society*, 17 October 2011 (online version).)

Bäumker, T. and Netten, A. (2011) *Examining Cost Variation Across Housing and Long-Term Care Schemes for Older People in England*. PSSRU Discussion Paper No. 2765/5, August 2011.

Bäumker, T., Netten, A., Darton, R. and Callaghan, L. (2011) *Evaluating Extra Care Housing in the United Kingdom Social Care Context: A Comparative Cost and Outcome Analysis with Residential Care*. PSSRU Discussion Paper No. 2766/5, June 2011.

Darton, R., Bäumker, T., Callaghan, L. and Netten, A. (2011) *Residents in Extra Care Housing: Changes in Dependency over Time, Survival and Destinations of Leavers*. PSSRU Discussion Paper No. 2775/2, March 2011.

Darton, R., Bäumker, T., Callaghan, L. and Netten, A. (2011) *Evaluation of the Extra Care Housing Initiative: PSSRU Technical Report*. PSSRU Discussion Paper No. 2783/2, December 2011.

Outputs from linked studies

Barnes, S., Torrington, J., Darton, R., Holder, J., Lewis, A., McKee, K., Netten, A. and Orrell, A. (2011) Does the design of extra-care housing meet the needs of the residents? A focus group study. *Ageing and Society*, 17 October 2011 (online version).

Bäumker, T., Netten, A. and Darton, R. (2008) *Costs and Outcomes of an Extra-Care Housing Scheme in Bradford*. Joseph Rowntree Foundation, York.

Bäumker, T., Netten, A. and Darton, R. (2010) Costs and outcomes of an extra care housing scheme in England. *Journal of Housing for the Elderly*, 24, 2, 151-170.

Callaghan, L., Netten, A. and Darton, R. (2009) *The Development of Social Well-Being in New Extra Care Housing Schemes*. Joseph Rowntree Foundation, York.

Evans, S., Vallelly, S. and Callaghan, L. (2010) *A Directory for Promoting Social Well-Being in Extra Care Housing and Other Settings*. Housing LIN Report No. 44, Updated January 2010. Housing Learning & Improvement Network, Department of Health, London.

Lewis, A., Torrington, J., Barnes, S., Darton, R., Holder, J., McKee, K., Netten, A. and Orrell, A. (2010) *EVOLVE: Evaluation of Older People's Living Environments*. http://www.housinglin.org/Topics/browse/Design/DesignGuides/?parent=6594&child=7997.

Lewis, A., Torrington, J., Barnes, S., Darton, R., Holder, J., McKee, K., Netten, A. and Orrell, A. (2010) EVOLVE: a tool for evaluating the design of older people's housing. *Housing, Care and Support*, 13, 3, 36-41.

Newsletters

Housing and Care for Older People Newsletter 1 (October 2006)

Housing and Care for Older People Newsletter 2 (January 2008)

Housing and Care for Older People Newsletter 3 (January 2009)

Evaluation of the Extra Care Housing Initiative, Newsletter (January 2008)

Evaluation of the Extra Care Housing Initiative, Newsletter (January 2009)

Housing and Care for Older People Programme News (February 2005)

Housing and Care for Older People Programme News (January 2006)

Selected posters and presentations

- Feedback Day, Department of Health, 29 November 2007
  Download all presentations [pdf, 73pp, 512KB]

- British Society of Gerontology Annual Conference, 4–6 September 2008
  Extra Care Housing for Older People: Emerging Findings from the PSSRU Evaluation and the Sheffield/PSSRU Study of Design
  Download all presentations [pdf, 65pp, 1.8MB]

- Feedback Day, Department of Health, 8 October 2008
  Download PSSRU presentations [pdf, 59pp, 457KB]
  Download workshop presentations [pdf, 35pp, 2.3MB]

- Housing and Care for Older People Research Network meeting, 22 October 2008
  The PSSRU Evaluation of the Extra Care Housing Funding Initiative
  Download presentation [PowerPoint file, 32pp, 775KB]

- IAGG World Congress of Gerontology and Geriatrics, 5-9 July 2009
  The Social Well-Being of Residents in Extra Care Housing in England
  Download poster [pdf, 52KB]

- British Society of Gerontology Annual Conference, 2–4 September 2009
  Extra Care Housing for Older People: Small Schemes and Care Villages – Their Strengths and Weaknesses
  Download all presentations [pdf, 12pp, 683KB]

- British Society of Gerontology Annual Conference, 2–4 September 2009
  The Economics of Housing and Care for Older People. PSSRU Evaluation of the Extra Care Housing Funding Initiative
  Download presentation [pdf, 3pp, 205KB]

- Feedback Day, Department of Health, 19 November 2009
  Download PSSRU presentations [pdf, 59pp, 295KB]
  Download workshop presentations [pdf, 81pp, 887KB]

- extraCare Conference, Linc Cymru & Cymorth Cymru, 10 June 2010
  Download PSSRU presentation 1 [pdf, 20pp, 192KB]
  Download PSSRU presentation 2 [pdf, 10pp, 161KB]

- International Conference on Evidence-Based Policy in Long-Term Care, 8-11 September 2010
  Download PSSRU presentation 1 [pdf, 22pp, 383KB]
  Download PSSRU presentation 2 [pdf, 14pp, 239KB]

- British Society of Gerontology Annual Conference, 5–7 July 2011
  Costs and Outcomes of Extra Care Housing
  Download all presentations [pdf, 9pp, 1.16MB]

- International Longevity Centre – UK Event, *Extra Care – A Sustainable Solution to the Care Crisis?*, 13 September 2011
  Download PSSRU presentation [pdf, 4pp, 185KB]

A web page containing links to the reports, including this document, and other documents produced about the evaluation is available on the PSSRU website: *www.pssru.ac.uk/projects/echi.htm*.

Information on the Department of Health's Extra Care Housing Programme, including the scheme locator and resources available for housing, health and social care professionals involved in the development of housing with care options for older people, is available on the Housing Learning and Improvement Network website: *www.housinglin.org.uk*.

About the PSSRU

The PSSRU was established at the University of Kent at Canterbury in 1974. From 1996 it has also had branches at the London School of Economics and the University of Manchester. The PSSRU aims to conduct high quality research on social and health care to inform and influence policy, practice and theory. The evaluation was conducted at the University of Kent branch of the PSSRU.

About the Housing LIN

The Housing LIN, formerly responsible for managing the Department of Health's Extra Care Housing capital programme, is now the leading 'knowledge hub' for housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing with care for older people.