Appendix 1 Methods of research

A1.1 Introduction

In Chapter 1 we provided a brief overview of the methods used in this study and linked them to specific objectives of the research (see Table 1). In subsequent chapters we provided a resumé of the methods used for the collection of data presented within the chapter. This appendix provides a full account of the research design and methods of research.

A1.2 Research design

The study employed a mixed-methods design (Cresswell, 2003) including: structured literature reviews of selected topics; telephone surveys of key organisations and individuals; focused-group interviews and one-to-one focused interviews with people with dementia, carers, front-line staff and service managers; and comparative case studies of six services providing respite care and short breaks using ethnographic methods (principally non-participant observation) and cognitive interviews.

A1.3 Literature reviews

Given the resources available we explicitly elected not to conduct formal structured or systematic reviews of the literature. Instead we: updated a structured review of respite care and short breaks for people with dementia and their carers (Arksey *et al.*, 2004); drew on a structured thematic review of person-centred care (Hughes *et al.*, 2008); and conducted a review of reviews to identify measures used in evaluating respite care and short breaks for people with dementia.

A1.3.1 Structured review of services providing respite care and short breaks

One strategy used to identify the range of models of respite care and short breaks (reported in Chapter 2) was updating an existing structured review undertaken in 2003 by a member of the research team (Arksey *et al.*, 2004). This examined the effectiveness of respite care and short breaks for carers of people with dementia but also identified service models that had been rigorously evaluated. The search strategy (Figure A1) was simplified and rerun at intervals throughout the project to identify papers published since the original review.

Figure A1 Simplified search strategy for identifying models of respite care and short breaks

1	(caregiv$ or care giv$ or carer$ or informal care or befriending or caretak$ or caretaker$ or care taker$ or care taking or children caring).ti,ab.
2	((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
3	((sons or daughters or friends) adj2 (care or caring)).ti,ab.
4	((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
5	(families caring or (families adj2 support)).ti,ab.
6	Caregivers/
7	or/1-6
8	Respite Care/
9	(care attendant$ or (support service$ or support program$ or support scheme$ or home support) or (short stay$ or break or breaks)).ti,ab.
10	day care/
11	(buddy scheme$ or befriending or night care or sitting).ti,ab.
12	(relief adj2 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
13	(holiday$ or vacation$ or residential home$ or respite or (day centre$ or day center$) or (day care or daycare or day program$ or day service$ or day away)).ti,ab.
14	(crossroads or (hotel$ or outing$) or personal assistant$ or leisure or time off or visitor$ or social club$ or friendship club$).ti,ab.
15	(home-based or inhome or temporary relief or homecare or home care).ti,ab.
16	(domicillary service$ or domicillary care or domiciliary service$ or domiciliary care or homemaker$ or (home help$ or home healthcare or home health care) or (home nursing or night nursing) or home service$ or home treatment$).ti,ab.
17	or/8-16
18	7 and 17
19	exp Dementia/
20	(dementia or demention or amentia or demented or dementing or confused or

	confusion).ti,ab.
21	(prion disease$ or Transmissible spongiform Encephalopathy or senile or Wernicke$ Encephalopathy or Bovine Spongiform Encephalopathy or Creutzfeldt Jakob Disease or Fatal Familial Insomnia).ti,ab.
22	Gerstmann Straussler Scheinker Syndrome.ti,ab.
23	(Scrapie or kuru).ti,ab.
24	Down Syndrome/
25	(down$ syndrome$ or down$ disease$ or mongoloid$ or mongolian or mongolism).ti,ab.
26	(Alzheimer$ or Corticobasal Degeneration or Diffuse Lewy Body Disease).ti,ab.
27	(senility or Huntington Chorea or Kluver Bucy Syndrome or Mental Deterioration or Minamata Disease or pick$ disease).ti,ab.
28	(Neuronal Ceroid Lipofuscinosis or Progeria or progressive aphasia).ti,ab.
29	(Rett Syndrome or supranuclear palsy or binswanger$ disease or Werner Syndrome).ti,ab.
30	Korsakoff Syndrome/
31	(korsakoff$ or vcjd or cjd or bse or mad cow disease).ti,ab.
32	Rett Syndrome/
33	Supranuclear Palsy, Progressive/
34	Werner Syndrome/
35	neurodegenerative diseases/ or exp prion diseases/
36	Wernicke Encephalopathy/
37	Neuronal Ceroid-Lipofuscinosis/
38	or/19-37
39	7 and 17 and 38
40	limit 39 to yr="2003 – 2008"

(Adapted from Arksey *et al.* 2004, Appendix 1).

The majority of databases searched in the original review were included in the updated search (Figure A2), with the exception of those to which we did not have access. Two additional databases on ageing were included (AgeInfo and

AgeLine). The formal search was supplemented with hand searches of selected journals to identify models of respite care and short breaks that had not been rigorously evaluated. The Dementia Services Development Centre at Stirling also conducted a search on our behalf to identify additional 'grey' literature. Since our emphasis was on identifying models of respite care and short breaks, we did not formally assess the quality of papers.

Figure A2 Databases searched for identifying models of respite care and short breaks

AgeInfo (Centre for Policy on Ageing)
AgeLine
CINAHL (Ovid)
CENTRAL (Cochrane Library CD-ROM)
Cochrane Database of Systematic Reviews (CDSR)
Current Controlled Trials
Database of Abstracts of Reviews of Effects (DARE)
EconLit (Silver-Platter)
EMBASE (Ovid)
Health Economics Evaluation Database (HEED)
Health Management Information Consortium (HMIC; Silver-Platter)
Health Technology Assessment Database (HTA)
International Bibliography of the Social Sciences (IBSS)
Internet Documents in Economics Access Service (IDEAS)
ISI Web of Science Proceedings
MEDLINE (Ovid)
National Research Register (NRR)
NHS Economic Evaluation Database (NHS EED)
PREMEDLINE (Ovid)
PsycINFO
Social Care Online
Social Science Citation Index (SSCI)
Sociological Abstracts (Silver-Platter)

We supplemented the literature search with a web search of selected UK sites. It proved difficult to create a search strategy that was sensitive and specific using search engines such as Google and Webfetch. We therefore concentrated on key

UK sites including the sites of local branches of the Alzheimer's Society, the Older People's Mental Health Mapping exercise (Barnes and Lombardo, 2006), the Commission for Social Care Inspection (CSCI) and Social Care Institute for Excellence (SCIE). Details of respite care or short breaks provided by the Alzheimer's Society were collated by the types available and their geographical location. We used the search facility in the Older People's Mental Health Mapping Exercise to identify services which appeared to meet our definition of respite care and short breaks. Details of relevant services were printed out and subsequently summarised, both in narrative form and in a spreadsheet.

A1.3.2 Structured review of centred care

Components of person-centred care are presented in Chapter 3. As part of another project, two of the authors of this report (CB and JH) reviewed the literature on centred care (Hughes *et al.*, 2008). Papers describing the components of person-, client-, family-, patient-, and relationship-centred care were identified using the search strategy shown in Figure A3. Selected papers were thematically reviewed to identify the key components of centred care. The ten components of centred care identified in this thematic review are presented in Table 5 (Chapter 3), together with components from other key frameworks.

Figure A3 Search strategy for review of centred care

Medline [a]	Patient adj (centred$ or centered$).ti
CSA Illumina [a, b]	(Patient AND centered) or (Patient AND centred)
Web of Science [a]	TI = Patient SAME (centred* OR centered*)

[a] The search was repeated for each database using the terms: person, client, family and relationship

[b] Selected databases were: AIDS and cancer research abstracts; ASSIA (Applied Social Sciences Index and Abstracts); CSA Linguistics and Language Behaviour Abstracts; PILOTS database; psycINFO; CSA social services abstracts; CSA sociological abstracts

A1.3.3 Review of measures used to evaluate respite care and short breaks for people with dementia

The findings of the review of measures used in the evaluation of respite care and short breaks for people with dementia and their carers are presented in Chapter 5. The starting point for the identification of measures was a review of reviews. We used the search in Figure A1, adding the term 'measure' or 'measures' and applying review filters (the Medline review filter and (http://www.sign.ac.uk/methodology/filters.html#systematic). We supplemented this with a broader search specifically focusing on observational measures used with people with dementia. We also searched the Proqolid database (Patient reported outcome and quality of life instrument database, http://www.qolid.org). Secondary reference and citation searches were also conducted. Copies of papers and details of identified measures were then obtained. Finally we reviewed policy documents containing standards or quality guidelines relating to respite care or short breaks.

The process of searching, retrieving and reviewing articles and other documents took place over a period of some six months. Toward the end of this period 'diminishing returns' were experienced with few additional appropriate measures being identified. This suggests that the majority, if not all, of the key measures, were identified.

A1.4 Telephone surveys

A1.4.1 Scoping survey

The target population for the scoping survey was organisations and individuals with a detailed knowledge of services providing respite care and short breaks across England and Scotland. The absence of any formal sampling frame for the target population militated against producing a representative sampling frame. We used a mixture of purposeful sampling (Strauss and Corbin, 1998), using information from the review of literature and websites, and snow-ball sampling (Miles and Huberman, 1984) starting with organisations identified by our Reference Group (see Chapter 1) and our existing research and service contacts. Participants in the telephone surveys were either known individuals or representatives of organisations contacted.

Semi-structured interviews were conducted with 22 individuals including representatives of Government agencies, statutory services in health and social care and non-statutory agencies promoting or providing either dementia care or support services for carers in England and Scotland. A further nine organisations were contacted, but we were unable to complete the interviews within the time available. The purpose of these interviews was to identify the range of models of respite care and short breaks known to participants, and to provide contact details for providers of different models. Interviews lasted on average 25 minutes. The topic guide used is shown in Figure A4.

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Figure A4 Topic guide for scoping telephone survey

1. Introduce self and remind the respondent about the project
2. Explain purpose of scoping survey (seeking examples of different models of respite care and short breaks for people with dementia of all ages)
3. Discuss our definition of respite care and short breaks
4. Ask what models of respite care and short breaks are available locally (nationally)?
5. Ask for a description of each model, probing for:
    - Setting
    - Clientele
    - Types of activities undertaken during respite care and short breaks
    - Pattern of use of service
    - When the service was established
    - Location
    - Any additional innovative features
    - Provider
    - Service manager
    - Whether any additional information about the service was available
6. Probe for any additional models (either local or national) and repeat question 5 until data has been gathered on all models
7. Check whether respondent knows of any evaluative studies of respite care and short breaks, if so, probe for:
    - Type of service evaluated
    - Type of evaluation, tools used and outcomes measured
    - Whether any publications about the evaluation are available
8. Check whether respondent can suggest other potential participants
9. Thanks and arrangements for sending feedback on the results of the scoping survey

The scoping interviews were audio-recorded with permission of the participant. Comprehensive notes were made of the data using specially designed structured forms that followed the main topic areas covered in the interview. Findings from the scoping survey are reported in Chapter 2. The sections of the interviews relating to person-centred care were transcribed for analysis (see Chapter 3).

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A1.4.2 Detailed telephone survey

Focused interviews were held with 36 key service providers from the statutory health and social care and non-statutory sectors (Table A1). The selected services were chosen to represent the range of both traditional and innovative respite provision in inner city, urban and rural locations, as well as services for specific groups of people with dementia such as younger people and people from minority ethnic communities. Representatives of organisations identified from the initial telephone scoping survey, the literature or web searches were approached by letter or e-mail and followed up by telephone. Participants were asked to nominate themselves or an appropriate individual in their organisation for a formal telephone interview. Interviews lasted on average 43 minutes. Participants were also asked to forward us supporting relevant documentation. The topic guide used is shown in Figure A5.

The interviews were audio-recorded with the permission of the participant. Key data were summarised on specially designed structured forms using appropriate headings. Findings of the detailed telephone interviews are reported in Chapter 2. The sections of the interviews relating to person-centred care were transcribed for analysis (see Chapter 3).

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Figure A5 Topic guide for detailed telephone survey with service managers

1. Introduce self and remind participant about the project including the purpose of telephone survey and the potential for further involvement in the study.
2. Seek consent for recording the conversation
3. Discuss our definition of respite care and short breaks
4. Confirm the respondent's role
5. For each model, probe for:
    - Service title
    - Description of service including:
        - Setting
        - Clientele
        - Aims of the service
        - Types of activities undertaken during respite care and short breaks
        - Pattern of use of respite care and short breaks
        - When the service was established
        - Location
        - Charges for respite care and short breaks
        - Transport arrangements (if relevant)
    - Any additional innovative features
    - Provider and budget
    - Referral routes into the service and any inclusion/exclusion criteria
    - Documentation available (e.g. annual report, documents used to facilitate care, induction process)
    - Whether there are any existing or planned service evaluations, if so, probe for:
        - Type of evaluation, tools used and outcomes measured
        - Whether any publications about the evaluation are available
6. Ask to what extent the respondent thinks the service provided is person- and carer-centred
7. Ask respondent whether there is anything else they would like to add about the service
8. Discuss interest in participating in Objective 2 and/or Objective 3
   Check whether respondent can think of anyone else or any other services (either locally or nationally) we should contact
9. Thanks and arrangements for sending feedback on the results of the scoping survey.

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Characteristics of participants in telephone surveys

The characteristics of the participating organisations are shown in Table A1. The descriptive findings of these two surveys are reported in Chapter 2.

Table A1 Characteristics of participating organisations in telephone surveys

Participant	Scoping interviews	Detailed interviews
Specialist with interest in dementia care, quality improvement or dementia research	8	0
Dementia Services Development Centres	4	0
Non-statutory organisations	10	20
Local authority social services departments	0	7
National health service	0	9
Total number of participants	22	36

A1.5 Focus groups and face-to-face focused interviews

The primary purpose of the focus groups and face-to-face focused interviews was to investigate the meaning of person-centred care in services providing respite care and short breaks for people with dementia and their carers. By exploring the meanings of person-centred care, we hoped to identify components that should be central to evaluations of respite care and short breaks. The analysis and interpretation of these data is described in Chapter 3. The data collected through these interviews also contributed to an analysis of facilitators and barriers to person-centred care (Chapter 4). The components of person-centred care and facilitators and barriers identified were subsequently used to evaluate the relevance of existing measures to person-centred care (Chapter 5) and to develop tools for evaluating person-centredness in services providing respite care and short breaks (Chapter 6).

A1.5.1 Sampling and recruitment to focus groups and interviews

In order to provide multiple perspectives from key stakeholders on the meaning of person-centred care our target populations were people with dementia, their carers, front-line staff and operational and strategic managers.

Initial contacts were made with strategic managers to discuss possible participation and identify research governance requirements. Once the necessary approvals were in place, access to potential participants was negotiated through service managers. Information leaflets were distributed by the service manager to front-line staff. Members of staff who were willing to participate completed and returned an opt-in form. Information was distributed to 50 members of staff, of whom 19 participated in either an interview or focus group. Service managers also distributed information to carers (including those who had declined or

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stopped using services, as well as current service users). Of the 140 carers sent information, 15 participated in either an interview or focus group. The initial approach to people with dementia was made by a known member of staff, usually during a routine face-to-face contact. Staff briefly outlined the study and asked the person with dementia whether they might be interested in taking part; if so, they sought permission to pass on the person with dementia's contact details to the research team. The research team then sent a letter and information leaflet to the person with dementia and followed this up with a telephone call to arrange an appointment to discuss the study further and to seek informed consent. Two people with dementia were recruited and took part in an interview. In addition, the manager of a service providing day care asked a group of people with dementia who attended on the same day whether they would take part in the study. All four people with dementia agreed and subsequently participated in a focus group. Written informed consent was obtained from all participants prior to data collection.

Recruitment of all stakeholders continued until data saturation was reached, with no new themes arising from additional interviews or focus groups. Participants in the focus groups and interviews had experience of a range of models of respite care and short breaks, either as service users, providers or commissioners (Table A2).

Table A2 Participants' experience of different models of respite care and short breaks

	People with dementia	Carers	Staff	All
Day care	5	6	7	18
Host-family day care	0	1	1	2
Social events or outings	0	1	1	2
Clubs, interest or activity groups	1	2	1	4
Home-based support	1	12	7	20
Adult placement scheme	0	0	2	2
Specialist respite facility	1	6	3	10
Respite beds	2	3	7	12
Holidays or short breaks	1	0	2	3
Total participants[1]	6	16	21	43

[1] The total number of participants is less than the sum of services used, since many participants used, commissioned or provided more than one service.

A1.5.2 Data collection in interviews and focus groups

Our previous studies exploring patient-centred care (Bamford *et al.*, 2007), quality of life (Corner, 2003) and outcomes for people with dementia (Bamford and Bruce, 2000), highlighted the difficulties of discussing these abstract concepts. Similarly, Innes *et al.* (2006) found that older people were not familiar with the term person-centred care and did not feel it described the care they received. We therefore developed topic guides that aimed to address the meanings of person-centred care through personal experience of services. Parallel topic guides were produced for people with dementia, carers (see Figure A6) and staff.

Figure A6 Topic guide used in focus groups and interviews (version for carers)

1. Introduce self and project
2. Housekeeping (toilets, timing, fire escape)
3. Explain purpose of interview/focus group. Explain our broad definition of respite care and short breaks
4. Discuss confidentiality and recording, obtain informed consent
5. Introductions, types of respite care and short breaks used (briefly)
6. Characteristics of a good episode of respite care or short break
   - Give examples of successful (and less successful episodes of respite) – discuss reasons for success (or lack of it)
   - How do you as a carer assess whether respite has been successful for the person you support?
   - Are the same characteristics important to carers and people with dementia?
7. Discussion of vignettes to illustrate different types of respite care and short breaks to prompt discussion of:
   - Whether the service appeals to the respondent and why
   - What the respondent sees as the positive and negative features of this type of respite care or short break and why
8. Ask the group to think about designing a new service that would provide an ideal break for **carers** of people with dementia. Ask each person to write down the three key characteristics. Repeat the exercise asking them to think about designing a new service that would provide an ideal break for **people with dementia**, and to write down the three key characteristics of the service.

   Discuss the similarities and differences between participants, first from each exercise separately, and then comparing the characteristics seen as important for carers and people with dementia.
9. Thanks, reminder about confidentiality, arrangements for sending feedback on the focus groups and interviews.

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Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

We used vignettes describing different models of respite care and short breaks to prompt discussion (Figure A7). Other models described in the vignettes were: home day care; clubs, interest or activity groups; home-based support (including sitting services); host-family respite; specialist respite facility; respite beds; and holidays.

Figure A7 Example of vignette used in focus groups and interviews

Sunnyvale is a purpose-built resource centre with a garden. The centre is open on weekdays between 9.00 am and 3.30pm. A minibus is available to collect people with memory problems from home. Men and women between the ages of 60 to 95 attend and carers can also join in if they wish. Meals and refreshments are provided. Staff and people with memory problems decide on activities which may include arts, crafts, baking, darts, gardening, computers, quizzes, household duties and outings. The activities are designed to maintain skills and encourage learning of new skills. A hairdresser and chiropodist also regularly visit the centre.

We also used an exercise to encourage 'blue-sky thinking' in which participants were asked to identify the key characteristics required of an ideal service providing respite care or short breaks (Figure A6). Focus groups were moderated by an experienced qualitative researcher, observed by another member of the project team and audio-recorded with participants' consent. Since not all stakeholders were willing and/or available to participate in focus groups, interviews (using similar topic guides) were used where appropriate. Three carer interviews were conducted by telephone, with written materials being sent in advance to facilitate discussion. All interviews were audio-recorded with participants' consent.

A1.5.3 Analysis of focus group and interview data

The focus groups and interviews were transcribed in full. All transcripts were checked by a member of the research team. The transcripts formed the formal data for the analyses reported in Chapters 3 and 4. A series of data workshops were held to identify themes in the transcripts and develop a coding frame. The development of the coding frame was somewhat challenging for a number of reasons. First, the different theoretical perspectives of members of the research team resulted in the data being approached and interpreted in widely differing ways. Second, the nature of the data collected was varied. Some professionals talked primarily at an abstract level, while other data focused more on a practical, concrete level. Developing a coding frame that was applicable to these different types of data was problematic. Third, there were problems in reaching consensus on an appropriate level of abstraction and detail for the codes. Finally, the wide range of services included added to the complexity of the data since participants' experience covered services with differing aims and priorities. As a result of these difficulties, the coding frame went through a number of iterations with varying levels of abstraction.

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We compared the draft coding frame with the ten components of person-centred care identified through a thematic analysis of the literature (Hughes *et al.*, 2008). This process resulted in a hybrid coding frame that simplified the structure of the draft coding frame derived from the transcripts by having a core set of codes each of which could be applied to people with dementia, carers or staff.

The hybrid coding frame was then applied to the transcripts from the interviews and focus groups. Two team members (MP and CB) worked closely together, initially coding the same transcripts and comparing codes. This process enabled the meanings of the codes to be clarified and the coding frame to be populated with examples from the data. Once there was strong agreement between these two coders, one member of the team (MP) undertook the remaining coding. NVivo was used to facilitate the coding of the data, and coding reports were produced and reviewed at regular intervals by the second coder. A summary of the output for selected codes was subsequently circulated to all members of the project team for discussion. No additional themes were identified and the coherence of the existing components was confirmed.

Once the transcripts had been coded, subsequent analyses focused on understanding the relationships between codes, and comparative analysis to explore whether the emphasis on different components of person-centred care varied systematically according to stakeholder group or to the service model(s) under discussion.

A1.6 Comparative case studies

Data collected as part of six comparative case studies (Yin, 1984) of respite care and short breaks are reported in Chapters 3 and 7. We did not undertake full ethnographies in each setting. Rather we made relatively brief visits to each setting to complete cognitive interviews on the tools developed and observe service provision.

A1.6.1 Selection and recruitment of services for the case studies

Six services were recruited, representing a range of models and providers of respite care and short breaks (Table A3).

Table A3 Services participating in case studies

	Type of respite care or short break	Provider
Service 1	Specialist resource centre	Social services
Service 2	Home day care	Non-statutory organisation
Service 3	Holidays	Non-statutory organisation
Service 4	Extended day care	Social services
Service 5	Day care	Non-statutory organisation
Service 6	One-to-one support	National Health Service

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

Our aim was to identify services for the case studies that reflected different models of respite care and short breaks and included NHS, Local Authority and non-statutory providers. Recognising diversity in people with dementia and their carers, we were also keen to access specialist services for younger people with dementia and people from black and minority ethnic groups. Services were geographically dispersed from the North East of England to the South Coast and included inner city, suburban and semi-rural areas. We initially contacted operational and strategic managers to discuss potential participation. We then sought research governance approval where appropriate. The work and time involved in obtaining ethical approval and research governance limited the number of case studies that could be completed within the time available. A brief description of the six services participating in the case studies is provided in Figure A8.

Figure A8 Description of services participating in case studies

Service 1 is a specialist resource centre for people with dementia. It is open 24 hours a day, 365 days a year. There are twenty beds for emergency use and short stays. A maximum of 6 weeks planned respite is available per year; this can be arranged on a rolling basis or when required.

Service 2 is a home day care scheme introduced in the year 2000. It operates five days a week (including Saturday), between the hours of 10 am and 3 pm. Trained and qualified care workers open up their home on the same day of each week to the same small (4-5) group of people with dementia, providing a friendly and safe domestic environment where they can relax and get to know each other. There are opportunities to join in activities, but no pressure to do so. Refreshments and a cooked lunch are provided. The service can support forty service users, the majority of whom have dementia.

Service 3 provides short holiday breaks for disabled people, and is run by a national charity. Three weeks each year are reserved for people with dementia and their carers. The Centre provides 24-hour care and personal support with a programme of activities, excursions and entertainment. The personal support is provided primarily by volunteers. There are 21 single rooms, six twin rooms and two suites.

Service 4 is a purpose-built day centre run by Social Services that caters for 12 people with dementia. The day centre is open 7 days a week and provides a range of activities and services, including transport and meals. The day centre is open from 8am to 8pm, although service users are only present between approximately 11am and 5pm. Overnight care is available on Mondays and Wednesdays.

Service 5 is an activity-based day centre run by a national charity. The day centre provides support and stimulation to people with dementia of all ages. There are places for 19 people with dementia with a ratio of staff to service users of 1:4. Activities are carefully planned with reference to the needs and interests of the individual and focus on maintaining and building on existing skills, providing stimulation and enjoyment, opportunities for social interaction and a sense of achievement.

Service 6 provides one-to-one support for people with dementia and their carers. To give the carer a break, a support worker will take the person with dementia out shopping, for a trip to the country or whatever best suits their individual needs. Approximately 30 people are registered with the service; service users must have a confirmed diagnosis of dementia. It is available between the hours of 7.00 am and 9.00 pm, seven days a week, 365 days of the year.

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The selected services did not did not reflect all our sampling criteria. Despite considerable efforts, we were unable to recruit a specialist service for black and ethnic minority groups. Although we contacted several organisations providing such services, changes in personnel or concerns about the workload involved meant that we were unable to recruit any specialist services. Similarly, specialist services for younger people with dementia were contacted. Although one such service was interested in taking part, the geographical distance from the research team and limited time and resources for fieldwork meant that it was not feasible to include the service. Our difficulties in locating and recruiting specialist services probably reflects the small number of such services. A small number of people from black and minority ethnic groups and younger people with dementia did, however, use the services included in the comparative case studies.

A1.6.2 Selection and recruitment of participants

Once participation was formally agreed, similar approaches to recruitment were adopted within each setting. Staff received an introductory letter and a project information sheet via the service manager. Where possible, the research team held a briefing meeting with staff to explain the purpose of the research and discuss participation. Since such meetings were not always possible, and not all members of staff were able to attend, we also discussed the project informally and recruited staff and volunteers during fieldwork. Written informed consent was obtained from all participating staff.

Carers received an information pack about the study either from the service manager, a known member of staff, or directly from the research team (following an initial approach by a member of staff). The information pack contained a letter outlining the study, a project information sheet, an opt-in form for carers and a form approving the participation of the person with dementia. Carers opting into the research were subsequently contacted by a researcher to discuss participation in more detail. Written informed consent was obtained from all carers prior to data collection.

Only people with dementia whose carers had approved participation were approached by the research team. A known member of staff briefly explained the study to the person with dementia and gave them an information leaflet. The researcher was subsequently introduced to the person with dementia and talked through the information leaflet with them. On the basis of this discussion, the researcher decided whether the individual had capacity to give informed consent to the observational element of the study. Individuals with capacity completed a written consent form. Where the person with dementia lacked capacity, a simple description of the project was given by the researcher in the presence of a member of staff. The member of staff was then asked to sign a form confirming that the person with dementia had been told about the project and that although s/he had not been able to give informed consent, s/he had shown no objection or signs of distress about being observed by the researcher. In all cases, we undertook to stop observing any people with dementia who showed signs of distress relating to their participation in the study, regardless of the type of consent given. People with dementia who gave informed consent for observation

were also invited to take part in a face-to-face interview. Individuals who were willing to take part completed an interview consent form. All interviews were audio-recorded with the person with dementia's consent.

The recruitment procedures were modified slightly in the service providing holidays. This service primarily focused on couples and was therefore the main setting in which observation of carers was feasible. (Carers typically had only limited or transitory contact with other services, limiting opportunities for observation). The manager of the holiday service had been unwilling to send out information to people with dementia and carers in advance. Consequently, all recruitment took place during fieldwork in this setting. We initially introduced ourselves to carers and people with dementia, described the study briefly, and gave them an information leaflet to read in their own time. We subsequently re-approached the couple and invited them to take part in the study. Where appropriate, we obtained written informed consent from each participant and also asked carers to complete an approval form.

A1.6.3 Overview of methods and data collected

The purpose of the comparative case studies was to test the tools developed and to 'validate' the framework of components of person-centred care. We used an iterative method simultaneously across the services participating in the case studies. The research team met regularly during the fieldwork period to review, modify and fine tune individual tools. Two main approaches were used: cognitive interviews and observation.

Cognitive interviews

The purpose of the cognitive interviews (Willis, 2005) with carers and front-line staff was to investigate the acceptability and relevance of the tools that we had developed to evaluate services providing respite care and short breaks (Chapter 6). Cognitive interviews are so called because they study the cognitive processes that participants use to complete research tasks such as responding to survey questions. In particular we were interested in participants' comprehension of questions and instructions; their ability to recall and make decisions; and their response processes. Cognitive interviews also have a wider goal of detecting a wide range of problems with research instruments. The techniques in cognitive interviewing involve both 'think aloud' and verbal probing procedures (Willis, 2005). We used cognitive interviews to 'test':

- self-completion questionnaire for carers
- self-completion questionnaire for staff (or volunteers) working in respite services for people with dementia
- vignettes for discussion by staff to explore their understandings of person-centred care.

We did not use formal cognitive interviewing methods to 'test' the structured conversational interview guide and accompanying photographs for people with dementia. Although cognitive interviews have been used successfully with people with dementia in a previous study (Corner, 2003), this was in the context of a

study in which relationships between the researcher and participants were developed over a period of months prior to the cognitive interviews. In the present study, there were limited opportunities to develop relationships with people with dementia prior to the interviews. We were concerned that a formal process of cognitive interviewing would be reminiscent of cognitive testing. Existing literature indicates that cognitive testing is often a negative experience for people with dementia (Cheston and Bender, 1999; Keady and Gilliard, 2002; Lai *et al.*, 2008). To avoid potentially negative consequences for people with dementia, we therefore chose not to conduct formal cognitive interviews in which respondents were explicitly asked to elaborate their understandings of the questions and the process of formulating their responses. Instead, we audio-recorded the interviews and transcribed them in full. This modified approach allowed us to achieve most of the aims of formal cognitive interviews.

Observation

The main purpose of observation within each service was to explore the range of components of person-centred care and how these were created (or undermined) moment by moment in the routine delivery of respite care and short breaks. Spradley (1980) describes participant observation as a continuum: non-participation, passive participation, moderate participation, active participation and full participation. Each of these constructs emphasises the way that participation and observation privilege the perspective of the observer, with or without appropriate reflexivity, rather than the perspectives of the observed. Our approach was to do non-participant observation recognising that all observation is both interactive and negotiated (Wind, 2008).

Overview of data collected

Table A4 summarises data collected in each of the services participating in the case studies.

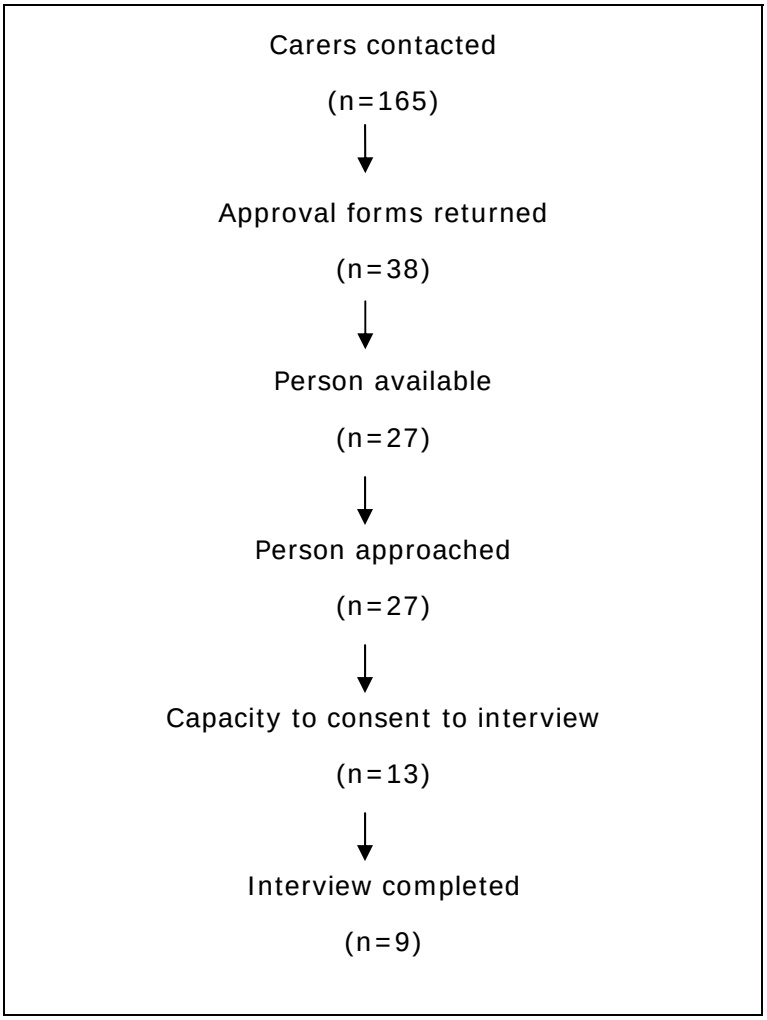
Table A4 Summary of data collected in the case studies

	Service 1	Service 2	Service 3	Service 4	Service 5	Service 6	All Services
Interviews with people with dementia	1	0	1	3	4	0	9
Cognitive interviews of carer questionnaire	6	4	5	6	6	3	30
Cognitive interviews of staff questionnaire	10	4	5	3	6	9	37
Cognitive interviews of vignette discussion with staff	2 groups	1 group 1 interview	0	2 groups	0	1 group	6 groups 1 interview
Total duration of observation (hours)	3.8	7.8	20.3	6.8	2.2	10.5	51.3

A1.6.4 Interviews with people with dementia

A copy of the conversational interview guide is provided in Appendix 3. A total of nine conversational interviews were completed with people with dementia (Figure A9). Although 165 carers were approached, only 38 returned approval forms. Almost one-third of the people with dementia for whom we received carer approval were not available for interview. Although researchers tried to maximise recruitment by carefully arranging fieldwork on days when people with dementia for whom we had approval would be present, this was not always possible. Some people with dementia were not available due to admission to long-term care (n=3) or other change in circumstances (n=2). Half of the people with dementia approached by a researcher were not thought to have capacity to consent to participation in an interview. Lack of capacity was a particular problem within the specialist resource centre and the holiday setting, suggesting that these services may be utilised more frequently by people with more severe impairment. Of the nine participants, five were female and four were male.

Figure A9 Recruitment of people with dementia



The interviews with people with dementia generally took place during respite care or short breaks. Since this could potentially have led to response bias, for example, if the person with dementia was concerned about critical responses being overheard, we tried to hold the interviews either in a separate room or in a quiet corner of the main room. The overall aim of the interviews was to test the conversational interview guide to see whether it was acceptable to people with dementia and to examine how well individual questions worked in practice.

The interviews were audio-recorded. During the interview we observed participants' responses, noting down any hesitancy, pauses and requests for elaboration. We encouraged participants to elaborate on their responses by using neutral probes, such as 'can you tell me more about that?' or by simply repeating what they had said.

Two people with dementia were asked indirect, as well as direct, questions. This was to explore the feasibility of using photographs and whether the use of indirect questions enabled criticisms to be articulated more easily.

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Analysis of interviews with people with dementia

The interviews were transcribed in full. The transcripts were examined carefully focusing on:

- how the wording of the questions was changed in practice
- whether the questions were repeated or elaborated
- whether the person with dementia seemed to understand the question (as indicated by requests for elaboration; spontaneous comments on the question; and whether the response given seemed related to the question asked)
- how responses were elaborated or changed during further probing
- whether the person with dementia was able to answer the question (as indicated by explicit comments by participants or difficulties in recall).

We also gave people with dementia the opportunity to add any further comments about their experience of the service, since this might identify any issues not covered in the interview guide. This approach achieved many of the aims of formal cognitive testing, particularly in terms of individual questions. We did not, however, collect data on question order. The issue of response options was not relevant to the conversational interview guide, since participants simply responded in their own words. As part of the analysis of the transcripts, we examined the range of responses given and developed draft response options which could be used. The intention would be to continue to allow participants to respond in their own words, but for the interviewer to then allocate responses to pre-coded response options.

A1.6.5 Cognitive interviews of carer questionnaire

A copy of the final version of the carer questionnaire is provided in Appendix 5. A total of 30 cognitive interviews were completed with carers (14 men and 16 women). Of these the majority (20) were spouses and the remainder were adult children (10).

Interviews generally took place in carers' own homes but there were exceptions. We conducted telephone interviews with two carers, and a handful of interviews took place in public areas, for example, the lounge of a holiday setting. The overall aim of these interviews was to find out how well the carer self-completion questionnaire worked as a whole, as well as the extent to which individual items were successful or not.

Participants in telephone interviews received the self-completion questionnaire in advance. For those participating in face-to-face interviews we started the interview by giving the questionnaire to participants, asking them to assume that it had arrived in the post and to complete it as though we were not present. During this time, we watched them answer the questions, noting down any

hesitancy, pauses, and expressions of puzzlement and so on. We subsequently questioned participants about these reactions.

The primary techniques adopted for conducting the cognitive interviews were verbal probing and observation, although on occasions some participants spontaneously 'thought aloud'. At the start of the interview, we reassured participants that the process of completing the questionnaire was not a test of their ability, but rather a test of our expertise at questionnaire design. In a few cases, the person with dementia was also present which might have affected carers' responses. Having completed the questionnaire, in the subsequent discussion we encouraged participants to be critical and identify problems either with single questions or the overall document. Whilst we were interested in the actual answers given, finding out how people arrived at those answers was the priority.

We developed a cognitive interview guide comprising focused and more general questions intended to explore participants' thought processes and specifically to elicit the extent to which they:

- understood the intended meaning of the questions (especially with regard to negative questions)
- considered the language used was appropriate, clear and unambiguous
- thought the questions were relevant, and in the right order
- felt that the response options were appropriate
- understood the questionnaire instructions.

We also asked carers' opinions about: the content of the questionnaire; question wording and sensitivity; layout and presentation; and overall length of the questionnaire. With agreement, interviews were audio-recorded and the researchers made hand-written notes during the interview.

Analysis of cognitive interviews with carers

Analysis of probed interviews is normally informal, rather than involving the application of a formal coding system (Willis, 2005). In our case, the analysis comprised two main stages. First, we reviewed and documented individual interviews and second, we compared the results across all the various sets of interviews. This was accomplished by listening to the audio-recordings and summarising participants' responses and comments. These were recorded in a series of Excel spreadsheets. Essentially, the spreadsheets were electronic copies of the questionnaires. Each individual survey question was included in the appropriate row in the spreadsheet; there was also space to record general comments about visual layout, overall length and the like. Each column in the spreadsheet was then used to summarise the responses of individual participants. We included verbatim speech, and also our own notes, if relevant. In this way, we produced spreadsheets that combined interviews using the same version of the questionnaire conducted by all members of the research team. These 'master' sheets helped us to identify issues that caused difficulty, and also to assess the

frequency/severity of problems that emerged. In this way, the data helped inform subsequent iterations of the questionnaires.

A1.6.6 Cognitive interview of staff questionnaire

Thirty-seven staff (28 female and nine male) completed a cognitive interview. The majority of participants were front-line staff (23); we also included two members of night staff, two volunteers and ten staff with management responsibilities (either team leaders or service managers). The conduct and analysis of cognitive interviews with staff were similar to the approaches used with carers. A copy of the final version of the staff questionnaire is provided in Appendix 6.

A1.6.7 Cognitive interviews of vignette discussion with staff

Vignettes were developed to represent feasible and quite common events or scenarios which could be managed in a range of ways (Chapter 7). Three vignettes were produced and brought together in a single document (Appendix 7). In developing the vignettes we drew on information from the focus groups and interviews conducted earlier in the study as well as our own experiences of respite care and short breaks through previous research projects. Group cognitive interviews with staff to discuss the vignettes were conducted in four of the six services participating in the case studies. The limited availability of staff meant that we were unable to arrange discussions in Services 3 and 5. Across the other four services, a total of 20 staff took part in six group cognitive interviews. These lasted an average of 40 minutes, and were facilitated by a research team member. One cognitive interview was arranged with a member of staff who was unable to attend the group discussion.

At each focus group participants were given a copy of the vignette document and asked to read the introductory front cover before proceeding to read one of the three vignettes. Vignette 1 (Jack and Susan) was used four times; vignette 2 (Bob and Doris) was used once; and vignette 3 (Gladys and Lisa) was used twice.

The facilitator asked participants: to identify the key issues for the three actors (person with dementia; carer; staff) in the particular vignette; to consider what staff could do to improve the situation; and to comment on the vignette's perceived authenticity.

For the second part of the discussion, participants were asked to read the text on 'Applying this approach to everyday practice' in the document (Appendix 7). This asked them to identify a service user and/or carer with whom they had difficulties in providing person-centred care, and then to consider the important issues for the person with dementia, carer and staff, and how the situation could be helped. They were also asked to highlight what could be learned from the discussion to improve the service in the future.

Finally, participants were asked their views about the value of the vignette activity as a tool for thinking about person-centred care, staff and organisational learning and reflecting on how to improve service delivery.

Each vignette discussion was audio-recorded and transcribed. An Excel spreadsheet was developed to record the data, which were analysed according to the following themes: the extent to which the scenario was realistic; how 'easy' the discussion was; whether participants were able to apply the approach to a person with dementia or carer known to the service; and participants' ability to engage in discussion of person-centred care.

A1.6.8 Observation

Since the intention of the case studies was to explore the extent to which the draft framework of components of person-centred care captured and reflected routine practice, it was important to avoid imposing structure on our observations. We were mindful of the potential of being 'blind' to data that did not readily fit into the framework. We therefore explicitly decided against using the draft framework of components as a guide to observation. Instead, we aimed to write detailed field notes as closely as possible in time to the period of observation since this facilitates memory recall (Mulhall, 2003). As 'outsiders', our perspective was to question practices and assumptions that were taken for granted with the aim of understanding how these related to the delivery of person-centred care. Through observation, supplemented by informal conversations, we examined the:

- nature of interactions (who interacted with whom; where and when interactions took place; the duration of interactions; who initiated and ended interactions; the focus of interactions)
- physical environment (how the nature of the physical environment impacted on routines, interactions and experiences of people with dementia, carers and staff)
- organisation and structure of the respite period (what happened, to whom and when; how decisions over activities were made; the purpose and beneficiaries of routines).

Reflecting the diversity of our case studies, observation took place in a range of settings including: institutional settings; family homes (either of the person with dementia or, in the case of home day care, hostesses' homes); various types of transport used by services (cars, minibuses and coaches); cafes and other services visited on outings. The role taken by the researchers similarly varied according to the fieldwork setting. Within institutional services, it was relatively easy to be unobtrusive and to primarily take on the role of non-participant observer. In contrast, researchers took a more active role in domestic settings or when eating meals or going on outings.

Data collected through observation is unlikely to be a true reflection of what happens in the absence of the observer, because participants are likely to change their behaviour in the presence of observer(s) and/or because of the influence of observers' professional and personal worldviews (Banister *et al.*, 1994; Coffey, 1999). We aimed to increase our awareness of how our personal worldviews influenced the nature and interpretation of data in two ways. First, by involving more than one observer in fieldwork at each setting; this was only possible in

three of the six services. Second, all field notes were reviewed by other members of the team, who were able to draw attention to underlying assumptions, ask clarifying questions and highlight areas where additional data were needed.

Overview of observation data collected

An average observation period of just over four hours in each setting was achieved (Table A4). Individual periods of observation ranged in duration from five to 260 minutes (mean duration 93 minutes, median 60 minutes). A disproportionate number of observations (14) were conducted in the holiday service. This was partly due to the difficulties in organising cognitive interviews in this setting, and partly due to the fact that two researchers were present continuously for two long days at the service. Only one continuous period of observation lasted longer than three hours; it has been suggested that this is the point when observational research might become intrusive and/or fatiguing for people with dementia and carers (Briggs *et al.*, 2003).

A summary of the observation periods, duration of observation and the numbers of stakeholders involved in observation is shown in Table A5.

Table A5 Summary of observation data collected

	Service 1	Service 2	Service 3	Service 4	Service 5	Service 6	All services
Periods of observation	6	2	14	5	3	3	33
Total duration of observation (hours)	3.8	7.8	20.3	6.8	2.2	10.5	51.3
People with dementia observed	4	3	7	6	4	3	27
Carers observed	0	0	7	0	0	3	10
Staff observed	15	2	8	6	2	3	36
Volunteers observed	0	0	7	0	0	0	7
Total number of people observed	19	5	29	12	6	9	80

Analysis of observation data

The field notes provided the data for analysis. The notes were imported into a qualitative data analysis package (NVivo) and coded by one member of the research team (CB) using the draft framework of components of person-centred care. A second member of the team (JH) reviewed the coding; discrepancies were discussed until consensus was reached. Sections of the field notes that did not appear to relate to any of the components of person-centred care were discussed in detail in order to identify any additional components. A summary of positive and negative examples of each component of person-centred care in relation to people with dementia and carers was produced to provide practical examples of person-centred care in routine practice (see Appendix 2). We also used the observation data to 'validate' responses to the tools. For example, the extent to which people with dementia were listened to; how choice was enacted in practice; and the types of activities on offer.

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Appendix 2 Examples of components of person-centred care from field notes

Table A6 Respecting individuality and values

	Examples of respecting individuality and values	Examples of a lack of respect for individuality and values
Person with dementia	The member of staff then asked the person with dementia whether he wanted to take his coat off (he was still wearing it from before lunch) and the person with dementia agreed and handed his walking stick to the member of staff. The staff member did not rush the person with dementia at all. The person with dementia took his coat off quite slowly and then proceeded to check all of the pockets carefully. At one point, the member of staff noticed that he was trying to check a pocket from the inside of the coat, and pointed out that he could get at it from the other side and helped him to lift up the flap over the pocket and check it. The member of staff then said that he would take the coat back to the person with dementia's room together with the stuff in the pockets. The person with dementia seemed quite happy with this. (Field notes, Service 1: 62-70)	After several people with dementia had already sat down at the dining tables, p403 said that she needed to go to the toilet. One member of staff asked if she was "desperate, desperate" to go. This was said loud enough so that I could hear it from where I was sitting and could also have been heard by the other service users. The service user must have said 'yes', as the staff then took her to the toilet. Because this service user is in a wheelchair, and has to be hoisted to use the toilet, both members of staff had to assist. This meant that all of the remaining service users were left alone. It took a reasonable amount of time for the service user to use the toilet, and I noticed that at one point, both members of staff had withdrawn and left her alone in the toilet. The service user subsequently pressed the alarm, presumably when she was ready, and the staff returned to the toilet to help her back into her wheelchair. (Field notes, Service 4: 267-275)
Carer	One person with dementia had apparently grudgingly given permission for his wife to go out for a meal with the other carers without him. His wife was anxious about leaving him. A member of staff promised his wife that she would phone the Centre when the carers arrived at the hotel to check whether her husband was ok. The member of staff also said that she would bring his wife straight back to the Centre if there were any problems. The member of staff further said that his wife could phone up again later in the evening, and reassured her that the volunteers at the Centre would be honest with her about how her husband was managing without her. (Field notes, Service 3: 1094-1099)	The carer had commented to me that he would raise his concerns about the volunteer with staff, but predicted that they would say it was a 'personality clash'. I subsequently overheard a conversation between two members of staff discussing the fact that the carer was not getting on with the volunteer assigned to him on this holiday. One member of staff commented that the carer had been 'spoilt' by having the same volunteer on a number of previous holidays and described him as 'overbearing'. Their response did not seem at all sympathetic or to take the carer's concerns seriously. (Field notes, Service 3: 1376-1381)
Staff	One person with dementia gives the hostess a bar of chocolate when she picks her up as she knows she's a chocoholic. (Field notes, Service 2: 181-182)	One member of staff mentioned that the day centre had few resources for activities. She occasionally bought jigsaws or similar items from charity shops for the day centre, but reported that it was really difficult to get the money reimbursed by the manager. (Field notes, Service 4: 541-543)

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Table A7 Enhancing psychological well-being

	Example of enhancing psychological well-being	Example of undermining psychological well-being
Person with dementia	One person in particular was reluctant to have a go, and repeated several times that he did not want to do it. However, s408 gave some strong encouragement for him to join in, stressing that **everyone** was going to have a turn. Eventually he agreed to have a go. He then became very animated and really seemed to enjoy himself. (Field notes, Service 4: 346-350)	On my last day at service 4, I noticed that p403's wheelchair had been positioned towards the dining end of the room, some distance from p401 and p402. When I asked someone about this, she said that when p403 was in a 'bad mood' they put her there on her own. (Field notes, Service 4: 532-535)
Carer	C304 had enjoyed the previous evening meal, even though she had been very anxious about leaving p304. She commented that she had not realised how much she had needed a break until she had one. (Field notes, Service 3: 881-882)	Around this time the carers were preparing to leave the centre to go out for a meal in a local hotel. Some of the carers were quite anxious about the possible reactions of their partners and concerned that there would be repercussions later. (Field notes, Service 3: 526-528)
Staff	S302 also discussed his personal reasons for moving from his previous post and some difficulties regarding stress and support, and the impact on home life. He also discussed feeling well supported at this centre. (Field notes, Service 3: 760-762)	The member of staff was anxious that she had still not received a permanent contract, despite reassurances from the manager that one would be forthcoming. She had now been working at the day centre for a number of months and wanted more job security. (Field notes, Service 4: 579-581)

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Table A8 Promoting autonomy

	Examples of promoting autonomy	Examples of a lack of autonomy
Person with dementia	When p104 joined us, s105 said that she would get her a tissue to wipe her mouth. When given the tissue p104 wiped her nose. S105 said that she had missed it and asked if p104 wanted her to wipe her mouth for her. When p104 said 'no', s105 then showed p104 where the biscuit crumbs were by pointing to her own face. This enabled p104 to wipe her face clean. (Field notes, Service 1: 328-331)	After the two members of staff had taken the person with dementia to the toilet, they took her straight back to the settee where she had been sitting all afternoon, rather than asking whether she wanted to walk around or have a look out of the window. When she got to the settee, she didn't seem to want to sit down. It could be that she actually didn't want to sit down or that she'd forgotten how to sit down. I had overheard a conversation on the previous day when a volunteer had said that the person with dementia liked standing. However, when the person with dementia didn't sit down after a short while, one member of staff subtly and gently used her shoulder to push the person with dementia down onto the settee. The person with dementia didn't seem to object to this. (Field notes, Service 3: 1423-1431)
Carer	A member of staff described how difficult it was for p403 to remain at home. She felt that care at home was on the verge of breaking down, but thought the family were unable to make the decision to arrange long-term care for p403. She suggested that the family almost wanted the service to make the decision for them, but was very clear that it was up to the family to make the decision, and that the service would continue to support the family as much as possible in the meantime. (Field notes, Service 4: 149-154)	There were no staff or volunteers around to make hot drinks, so one carer asked me whether she could make herself and her husband a drink. There was a small kitchen area which guests could use; however, the carer was not aware of this. She found it quite difficult to locate things in the kitchen and was not sure how to use the hot water dispenser. This was the fourth day of the holiday, so I was surprised that no-one had explained the arrangements to her. (Field notes, Service 3: 1461-1469)
Staff	I asked a member of staff about the arrangements for taking service users out of the building. She felt the decision to take service users out was up to individual members of staff. She thought that she knew individual service users well enough to judge whether they would 'do a runner' or just wanted a bit of fresh air. (Field notes, Service 1: 260-266)	

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Table A9 Promoting a sense of shared responsibility

	Example of promoting shared responsibility	Example of undermining shared responsibility
Person with dementia		
Carer	S601 asked them both how they were, and c603 said he was a bit cross because he'd just had a phone call cancelling p603's Thursday session which was irritating as he had a hospital appointment at 11.30. S601 did her best to find out when he thought he would be back from the hospital appointment (about 1.30pm), and then she rang through to the office to try to get the Thursday visit reinstated. (Field notes, Service 6: 416-421)	Her husband had been attending the day centre five days each week (Mon to Fri). Recently though, following an incident with another service user, his days had been changed to Tues, Thurs, Sat and Sunday without any prior consultation with the carer. This had not been very good for the carer as she had lost a day and her husband now attended at weekends which were easier for her to manage anyway. (Field notes, Service 4: 210-212)
Staff	The manager said that there was an ongoing debate among the staff team about how best to manage p104. She wanted to stay in bed all day, even though she went to bed relatively early (at 8pm). Although the manager could see an argument for letting her stay in bed as much as she liked, the manager was also concerned that p104 was incontinent and hadn't had anything to drink since the previous day. The manager therefore felt that on balance p104 should get up, although this view was not shared by all staff. (Field notes, Service 1: 497-502)	

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Table A10 Fostering social context and relationships

	Example of fostering social context and relationships	Example of undermining social context and relationships
Person with dementia	On at least two occasions, and without any prompting p201 cuddled up to the woman sitting next to her. On one occasion, p201 said to her 'We are good friends; I think it's very nice' (Field notes, Service 2: 336-337)	The feedback from a member of staff on duty at the weekend had been that her husband had been a bit lost as he did not know the other people at the day centre at the weekend. He had previously been attending for 3 years and had got to know the other service users on the days he attended. (Field notes, Service 4: 212-215)
Carer	He felt the holiday provided a social context for carers to talk frankly to other people about the situation they are in; this included discussion of 'unmentionables' and 'shocking' things. (Field notes, Service 3: 1509-1510	

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Table A11 Enhancing communication

	Example of enhancing communication	Example of a lack of communication
Person with dementia	On her return, she greeted p102 cheerfully and noticed he was drinking a cup of tea. The staff carer asked p102 if he would like a biscuit. She spoke in a loud, clear and positive voice, and engaged eye contact with p102. She also showed him a biscuit and made an eating gesture. She asked the question again, and p102 said that they had already had one and seemed hesitant. The staff carer said that he could have another and p102 asked whether he was allowed. The staff carer told p102 that he could have as many as he liked, and in a jokey nature encouraged p102 to have more and put another three chocolate biscuits on a plate and said, "naughty but nice!" (Field notes, Service 1: 198-205)	A further example was then given of a female service user whose moods were very volatile. Both s407 and s408 described how difficult it was to 'get round her' and to identify 'tactics' which worked for her. Again an example was given of difficulties arising during personal care: 'you try and have her go to the toilet, pulling her knickers down or helping her, and she would sort of freak out' (s408). (Field notes, Service 4: 187-190)
Carer	C405 was very pleased by the feedback she had received from the service; one member of staff had started a diary for p404 in which she wrote what he had been doing and what he had eaten. This clearly did not happen for other service users. C405 had also been very pleased to receive a photograph of p404 playing golf. This all contributed to her feeling that he was having a stimulating and interesting day. (Field notes, Service 4: 558-562)	Another issue related to the extent to which carers were aware of the range of services available. C405 struggled with bathing him at home as she didn't realise that he could have a bath whilst he was at day care. She had only found out by accident when she mentioned to a member of staff that she was thinking of getting a new bath. Although c405 had information leaflets about the service, she wasn't sure whether some aspects (such as bathing) applied only to residents in the attached residential home (Field notes, Service 4: 553-558)
Staff		She commented that because the service is open 7 days a week, staff do not always work with the same people. Communication is done through a message book, and she felt that sometimes you needed to know a little more information than was recorded. (Field notes, Service 4: 574-577)

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Table A12 Meeting physical and personal needs

	Example of meeting physical and personal needs	Example of failing to meet physical and personal needs
Person with dementia	P602 has had difficulty eating since his fall (s606 commented that he had lost quite a few pounds when she first arrived at the flat). They decided that he would have (tomato) soup in a mug and bread today instead of his usual sandwich, which would have been difficult to eat. (Field notes, Service 6: 274-277)	The volunteer then fed ice cream to the person with dementia for a lengthy period, wiping her chin regularly to get rid of the drips. [….] The person with dementia did not seem interested in the last couple of spoonfuls and I wondered why the volunteer persisted with them. With the last spoonful, the person with dementia gripped the spoon with her teeth, leaving the volunteer to wrestle it from her mouth. (Field notes, Service 3: 1088-1090)
Carer	V305 had selected their packed lunch for the outing and had also brought extra biscuits along. She mentioned that other staff had suggested that they take these as c304 had not eaten breakfast and may get hungry. (Field notes, Service 3: 320-322)	We left the house around 11.30-ish, after carer had put the person with dementia in the front passenger seat of the car – the support workers are not allowed to help with this job, nor can they help get the person with dementia out of the car when returning home. If the carer didn't put the person with dementia in the car, then she would not be able to go out on trips. The member of staff argued 'tooth and nail' at the time that the number of support workers was reduced from two to one, that the person with dementia should still be able to go out. This arrangement (i.e. that the carer took responsibility for getting the person with dementia into and out of the car) was the compromise. This seemed to simply shift the health and safety concerns from the worker to the carer – who was considerably older. (Field notes, Service 6: 45-51)
Staff	I had noticed that there were staff toilets as well as a male and female toilet for service users. I asked a member of staff the reasons for having separate staff toilets. She comments that some service users were 'very dirty' in the toilets […] and emphasised that the toilets sometimes got really mucky and had to be given a really good clean at the end of the day. She explicitly said that 'you really wouldn't want to go in them'.* (Field notes, Service 4: 125-131)	She described how a person with dementia had suddenly turned and chased after her and another member of staff when he was changing into his pyjamas one night. The person with dementia was very large and the member of staff reported being quite scared. (Field notes, Service 4: 180-182)

* Clearly this is also an example of a lack of respect for service users, since the same standards of cleanliness did not apply to them.

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Table A13 Developing a therapeutic alliance

	Example of developing a therapeutic alliance	Example of failing to develop a therapeutic alliance
Person with dementia	She lost a niece, who was quite a youngish woman. She was upset and didn't really want to go to Home Day Care that day, but her daughter 'persuaded' her to go. She didn't say anything to anyone at the group. S202 dropped her off at home at 3pm, and unusually went in and sat with her for a while and asked if she was feeling better. P203 said that this showed s202's caring side, and commented that she didn't have to do that. (Field notes, Service 2: 170-174)	
Carer	C603 mentioned that they were going to a funeral on Thursday, p603's sister had just died. P603 was now the only one left, as her other sister had died a while ago. Being reminded about her sister(s) and the funeral shook p603 and she went quite quiet and looked a bit tearful. S601 was shocked, as she had not known so all of a sudden the whole atmosphere changed from being fun and laughter to solemn and weepy – all in the space of a few seconds. S601 talked to both of them about their relationships with the two sisters, now both dead, and within about five minutes things were getting back to normal. (Field notes, Service 6: 547-554)	

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Table A14 Valuing expertise

	Example of valuing expertise	Example of failing to value expertise
Person with dementia		
Carer		The carer showed the member of staff how to use the syringe, explaining that she should use one side of the person with dementia's mouth where there was a missing tooth which made it easier to give the juice. He also stressed that she should wait for the person with dementia to swallow the juice before giving any more. Finally, he said that she shouldn't give a whole syringeful at a time. I was able to watch the member of staff giving the juice whilst I was talking to the carer. She started by giving the person with dementia a large syringeful and then asked whether she wanted any more. When the person with dementia said nothing, the member of staff assumed this meant that she didn't want any and did not attempt to give her any more [….] at some point the carer turned round and commented that there was no point asking the person with dementia, but that the member of staff should just persevere with the juice. The member of staff did not seem to take any notice of this beyond immediately administering another syringeful, but then went back to just sitting with the person with dementia and occasionally asking whether she wanted more juice. Later on when it got near to lunch time, the carer turned and commented that the person with dementia had had hardly any of the juice. He then proceeded to administer the rest himself, which was achieved fairly quickly and without any reluctance from the person with dementia. (Field notes, Service 3: 1344-1361)
Staff	After several unsuccessful attempts to try to get the person with dementia to take his medication, the member of staff said that she might phone the nursing home to see how they usually managed his medication. (Field notes, Service 3: 998-1000)	A senior member of staff commented that staff felt helpless with p104 and didn't know what to do to help her. He felt this was one factor contributing to the idea of allowing her to stay in bed as long as she likes. (Field notes, Service 1: 506-508)

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Appendix 3 Conversational interview guide for people with dementia

The guide consists of core questions plus supplementary questions relevant to some services or situations. In organising the core questions we developed different questions for communal and one-to-one support services. For each service type, direct and indirect questions were produced resulting in four versions of the core questions:

- direct questions for communal services
- indirect questions for communal services
- direct questions for one-to-one support services
- indirect questions for one-to-one support services.

The relationship between individual questions and the components of person-centred care is summarised in Table A15.

Table A15 Components of person-centred care covered in the conversational interview guide for people with dementia

Component of person-centred care	Relevant questions
Respecting individuality and values	4, 11, S6, S7
Enhancing psychological well-being	5, 8, 9, 14, 15, S4
Promoting autonomy	2, 3, 6, 7, S4, S5
Promoting a sense of shared responsibility	6
Fostering social context & relationships	8, 9, S1, S2, S11, S12
Enhancing communication	12, 13
Meeting physical & personal needs	S3, S5, S6, S7, S8, S9
Developing a therapeutic alliance	9, 10, S10
Valuing expertise	

The final version of the conversational interview guide with direct questions for communal services is included below. Single asterisks are used to identify questions which were modified or added towards the end of the fieldwork and therefore require further evaluation. The front page of the guide provides the list of prompts used in introducing the questions in the present study. The prompts and instructions would need to be tailored to the specific service and procedures

for gathering and using information before being used elsewhere. The photographs used in the present study reflect the characteristics of participants. A wide range of photographs would be needed in practice to ensure that respondents from black and minority ethnic groups could choose a photograph of a person from a similar ethnic background, age and gender. The ways in which the core questions were rephrased for use in one-to-one services and for indirect questions are summarised in Table A16.

Conversational interview guide for people with dementia

Core direct questions for communal services

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THE UNIVERSITY of York
S | P | R | U
SOCIAL POLICY RESEARCH UNIT

INSTITUTE OF HEALTH AND SOCIETY
Newcastle University

Your views of <service name>

Direct questions for communal services

(Including home day care, day care, specialist resource centres, residential and nursing homes)

- If you have just completed the consent procedure, introduce the questions by saying that you would now like to start the interview.
- If the consent procedure was completed on a previous occasion, re-introduce yourself to the respondent and remind him/her about the study. Check that s/he is happy to go ahead with the interview.
- Ask permission to record the interview before switching on the recording equipment.
- On completion of the interview check whether the participant is happy for us to use the information.
- If the respondent seems fatigued at any point, suggest that you have a break. Remember to introduce yourself and the study again and to reconfirm consent before resuming the interview at a later date.
- Summarise the respondent's answers in the spaces provided.
- Allocate a code to the respondent's answer using the list provided.

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*1. What is it like here?

Probe: What sorts of things do you do here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

2. Supposing you fancied a cup of tea or coffee, what would you do?

If refreshments are at set times:

Probe: What if you are thirsty at another time?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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3. Can you go outside if you want to?

Probe: Who decides whether or not you can go outside?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*4. Do you ever feel rushed here?

Probe: Can you take as much time as you need to do things?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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5. Does much go on here?

Probe: Do you spend much time waiting around here?

Is there too much going on here?

Do you ever get bored here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*6. How much choice do you have over what you do when you are here?

Probe: Who decides what you do here?

How are decisions made?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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7. What happens if you don't want to join in with something?

   Probe: What would staff say if you didn't join in?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

8. Are there times when you feel a bit left out?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

*Show photographs of members of staff and explain that you would like to ask a few questions about the people who help here

If the service is provided by a single individual (e.g. home day care), use the person's name rather than 'the staff' in the following questions.

*9. How do you get on with the staff here?

Probe: Do you have a laugh with the staff here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

10. Do staff take an interest in you?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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11. How patient are staff with you?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

12. Do staff have time to talk to you?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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13. Are the staff good listeners?

Probe: Do staff have time to listen to you?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

14. How do you feel about coming here?

Probe: Do you mind coming here?

Do you enjoy coming here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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15. Do you look forward to coming here?

Probe: Do you worry about coming?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*16. Is there anything else you'd like to say about coming here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Table A16 Modified question wording for indirect questions and one-to-one services

Question	Indirect questions for communal services	Direct questions for one-to-one services	Indirect questions for one-to-one services
1	What would <photo name> think it was like here? Probe: What sorts of things would s/he do here? How would s/he describe it here?	What is it like spending time with <carer name>? Probe: What sorts of things do you do with <carer name>?	What would <photo name> think it was like spending time with <carer name>? Probe: What sorts of things would s/he do with <carer name>?
2	Supposing <photo name> fancied a cup of tea or coffee, what would s/he do? If refreshments are at set times: What if s/he was thirsty at another time?	Supposing you fancied a cup of tea or coffee when you were with <carer name> what would you do? If refreshments are at set times: What if you are thirsty at another time?	Supposing <photo name> fancied a cup of tea or coffee when s/he were with <carer name> what would s/he do? If refreshments are at set times: What if s/he was thirsty at another time?
3	Could <photo name> go outside if s/he wanted to? Probe: Who would decide whether or not s/he could go outside?	Can you go outside when you are with <carer name>? Probe: Who decides whether or not you can go outside?	Could <photo name> go outside when s/he was with <carer name>? Probe: Who would decide whether or not s/he could go outside?
4	Would <photo name> ever feel rushed here? Probe: Could s/he take as much time as s/he needed to do things?	Do you ever feel rushed by <carer name>? Probe: Can you take as much time as you need to do things?	Would <photo name> ever feel rushed by <carer name>? Probe: Could s/he take as much time as s/he needed to do things?

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5	Would <photo name> think there was much going on here? Probe: Would s/he spend much time waiting around here? Would s/he think there was too much going on here? Would s/he get bored here?	Does much go on when you are with <carer name>? Probe: Do you spend much time waiting around when you are with <carer name>? Is there too much going on when you are with <carer name>? Do you get bored when you are with <carer name>?	Would <photo name> think there was much going on when s/he was with <carer name>? Probe: Would s/he spend much time waiting around when s/he was with <carer name>? Would s/he think there was too much going on when s/he was with <carer name>? Would s/he get bored when s/he was with <carer name>?
6	How much choice would <photo name> have over what to do when s/he was here? Probe: Who would decide what s/he would do here? How would decisions be made?	How much choice do you have over what you do when you are with <carer name>? Probe: Who decides what you do when you are with <carer name>? How are decisions made?	How much choice would <photo name> have over what to do when s/he was with <carer name>? Probe: Who would decide what s/he would do when s/he was with <carer name>? How would decisions be made?
7	What would happen if <photo name> didn't want to join in with something? Probe: What would staff say if s/he didn't join in?	What happens if you don't want to do something <carer name> suggests? Probe: What would <carer name> say?	What would happen if <photo name> didn't want to do something that <carer name> suggested? Probe: What would <carer name> say?
8	Are there times when <photo name> would feel a bit left out?	Are there times when you feel a bit left out when you are with <carer name>? (For example, if <carer name> has a long conversation with someone else.)	Are there times when <photo name> would feel a bit left out when s/he was with <carer name>? (For example, if <carer name> had a long conversation with someone else.)

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9	How would <photo name> get on with the staff here? Probe: Would s/he have a laugh with the staff here?	How do you get on with <carer name>? Probe: Do you have a laugh with <carer name>?	How would <photo name> get on with <carer name>? Probe: Would s/he have a laugh with <carer name>?
10	Would staff take an interest in <photo name>?	Does <carer name> take an interest in you?	Would <carer name> take an interest in <photo name>?
11	How patient would staff be with <photo name>?	How patient is <carer name> with you?	How patient would <carer name> be with <photo name>?
12	Would staff have time to talk to <photo name>?	Does <carer name> have time to talk to you?	Would <carer name> have time to talk to <photo name>?
13	Would <photo name> think the staff were good listeners? Probe: Would staff have time to listen to <photo name>?	Is <carer name> a good listener? Probe: Does <carer name> have time to listen to you?	Would <photo name> think <carer name> was a good listener? Probe: Would <carer name> have time to listen to <photo name>?
14	How would <photo name> feel about coming here? Probe: Would s/he mind coming here? Would s/he enjoy coming here?	How do you feel about spending time with <carer name>? Probe: Do you mind spending time with <carer name>? Do you enjoy spending time with <carer name>?	How would <photo name> feel about spending time with <carer name>? Probe: Would s/he mind spending time with <carer name>? Would s/he enjoy spending time with <carer name>?

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15	Would <photo name> look forward to coming here? Probe: Would s/he worry about coming?	Do you look forward to spending time with <carer name>? Probe: Do you worry about spending time with <carer name>?	Would <photo name> look forward to spending time with <carer name>? Probe: Would s/he worry about spending time with <carer name>?
16	Can you think of anything else <photo name> would think about coming here?	Can you think of anything else you'd like to say about spending time with <carer name>?	Can you think of anything else <photo name> would think about spending time with <carer name>?

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The supplementary questions, to be used in specific situations, are shown overleaf. A distinction can be drawn between supplementary questions suitable for communal and one-to-one services. However, this distinction was not necessarily the most relevant factor, and additional information on situations in which individual supplementary questions are appropriate is provided below. The direct questions for communal services are shown in full, followed by a summary of how these were rephrased for use in one-to-one services or indirect questions (Table A17).

Conversational interview guide for people with dementia

Supplementary direct questions for communal services

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Relationships with other service users

S1. How do you get on with the other people here?

Probe: How would you describe the other people here?

Is there anyone here that you don't get on with?

Do you have a laugh with the other people here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

S2. Do other people like coming here?

Probe: How can you tell whether other people like it here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Overnight care outside the home

*S3. What is it like staying here overnight?

Probe: Are you able to get to sleep at night?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

S4. Can you stay up late if you want to?

Probe: Who decides when you go to bed?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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S5. Can you have a lie in if you want to?

Probe: Do you get enough sleep when you are here?

Do staff wake you up in the morning or let you sleep as long as you like?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Meals and food

*S6. How would you describe the meals/food that you have here?

Probe: What do you enjoy about the food here?

What don't you like about the food here?

Do you get plenty of time to eat your meals?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Personal care

*S7. Does someone help you to go to the toilet?

IF YES: Do they take you as soon as you want to go?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*S8. Do you ever have a bath here?

IF YES: What is it like having a bath here?

	Code
Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Transport provided as part of the service

*S9. How would you describe the bus/car journey to get here?

Probe: How comfortable is the bus/car?

What do you think about the length of the bus/car journey?

What do you enjoy/dislike about the bus/car journey?

Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

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Relationships with staff

(S10 and S11 apply where a number of staff are seen; S12 applies where only one member of staff is seen)

*S10. Are there any staff that you particularly like?

Probe: Are there any staff that you are not so keen on?

Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*S11. What do you like about seeing different staff?

Probe: What are the advantages of seeing different staff?

What are the disadvantages of seeing different staff?

Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

*S12. What do you like about seeing the same member of staff every time?

Probe: What are the advantages of seeing the same person every time?

What are the disadvantages of seeing the same person every time?

Positive	1
Positive with some reservations	2
Neutral	3
Negative with some positive aspects	4
Negative	5
Unable to answer	6
Unable to code response	7

Table A17 Modified question wording for indirect questions and one-to-one support services

Question	Indirect question for communal services	Direct question for one-to-one support services	Indirect question for one-to-one support services
S1	How would <photo name> get on with the other people here? Probe: How would s/he describe the other people here? Is there anyone here that s/he wouldn't get on with? Would s/he have a laugh with the other people here?	N/A	N/A
S2	Would <photo name> think other people liked coming here? Probe: How would s/he be able to tell whether other people liked it here?	N/A	N/A
S3	What would <photo name> think it was like to stay here overnight? Probe: Would s/he be able to get to sleep at night?	What is it like when <carer name> stays overnight? Probe: Can you get to sleep when <carer name> stays overnight?	What would <photo name> think it was like if <carer name> stayed overnight? Probe: Would s/he be able to get to sleep when <carer name> stayed overnight?

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S4	Would <photo name> be able to stay up late if s/he wanted to? Probe: Who would decide when s/he went to bed?	Can you stay up late if you want to when <carer name> stays overnight? Probe: Who decides when you go to bed?	Would <photo name> be able to stay up late if s/he wanted to when <carer name> stayed overnight? Probe: Who would decide when s/he went to bed?
S5	Would <photo name> be able to have a lie in if s/he wanted? Probe: Would s/he get enough sleep when s/he was here? Would staff wake <photo name> up in the morning or let her/him sleep as long as s/he liked?	Can you have a lie in if you want to when <carer name> stays overnight? Probe: Do you get enough sleep when <carer name> stays overnight? Does <carer name> wake you up in the morning or let you sleep as long as you like?	Would <photo name> be able to have a lie in if s/he wanted when <carer name> stayed overnight? Probe: Would s/he get enough sleep when <carer name> stayed overnight? Would <carer name> wake <photo name> up in the morning or let her/him sleep as long as s/he liked?
S6**	How would <photo name> describe the meals/food here? Probe: What would s/he enjoy about the food here? What wouldn't s/he like about the food here? Would s/he get plenty of time to eat the meals?	How would you describe the meals/food that you have with <carer name>? Probe: What do you enjoy about the meals/food you have with <carer name>? What don't you like about the meals/food you have with <carer name>? Does <carer name> give you plenty of time to eat your meals?	How would <photo name> describe the meals/food that s/he had with <carer name>? Probe: What would s/he enjoy about the meals/food s/he had with <carer name>? What wouldn't s/he like about the meals/food s/he had with <carer name>? Would <carer name> give her/him plenty of time to eat meals?

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S7	Would staff help <photo name> to go to the toilet? IF YES: Would staff take <photo name> as soon as s/he wanted to go?	Does <carer name> help you to go to the toilet? IF YES: Does <carer name> take you as soon as you want to go?	Would <carer name> help <photo name> to go to the toilet? IF YES: Would <carer name> take <photo name> as soon as s/he wanted to go?
S8	Would staff help <photo name> to have a bath here? IF YES: What would s/he think it was like having a bath here?	Does <carer name> help you to have a bath? IF YES: What is it like when <carer name> helps you to have a bath?	Would <carer name> help <photo name> to have a bath? IF YES: What would s/he think it was like when <carer name> helped her/him to have a bath?
S9***	How would <photo name> describe the bus/car journey to get here? Probe: How comfortable would s/he be on the bus/car? What would s/he think about the length of the bus/car journey? What would s/he enjoy/dislike about the bus/car journey?	How would you describe the car journeys with <carer name>? Probe: How comfortable is <carer name's> car? What do you think about the time spent in the car? What do you enjoy/dislike about the car journeys with <carer name>?	How would <photo name> describe the car journeys with <carer name>? Probe: How comfortable would s/he be in <carer name's> car? What would s/he think about the time spent in the car? What would s/he enjoy/dislike about the car journeys with <carer name>?

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S10****	Are there any staff that <photo name> would particularly like? Probe: Are there any staff that s/he would not be so keen on?	Are there any staff that you particularly like? Probe: Are there any staff that you are not so keen on?	Are there any staff that <photo name> would particularly like? Probe: Are there any staff that s/he would not be so keen on?
S11****	What would <photo name> like about seeing different staff? Probe: What would s/he think were the advantages of seeing different staff? What would s/he think were the disadvantages of seeing different staff?	What do you like about seeing different staff? Probe: What are the advantages of seeing different staff? What are the disadvantages of seeing different staff?	What would <photo name> like about seeing different staff? Probe: What would s/he think were the advantages of seeing different staff? What would s/he think were the disadvantages of seeing different staff?
S12****	What would <photo name> like about seeing the same member of staff every time? Probe: What would s/he think were the advantages of seeing the same person every time? What would s/he think were the disadvantages of seeing the same person every time?	What do you like about seeing the same member of staff every time? Probe: Are there any advantages of seeing the same person every time? Are there any disadvantages of seeing the same person every time?	What would <photo name> like about seeing the same member of staff every time? Probe: What would s/he think were the advantages of seeing the same person every time? What would s/he think were the disadvantages of seeing the same person every time?

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** This would include eating out as well as meals prepared by the member of staff

*** The most appropriate version of supplementary question 9 depends on the type of transport used and the main purpose of the transport. Outings are key activities in some one-to-one services, but may be irrelevant to other services.

**** Questions 10 and 11 apply when the service is provided by a number of members of staff; question 12 applies when the service is provided by a single member of staff. This is not necessarily linked to service type since home day care (a communal setting), typically involves only one member of staff; respondents receiving one-to-one support services do not necessarily consistently see the same member of staff, but may routinely see two or three different members of staff each week. The choice of question will therefore depend on the specific experience of the respondent.

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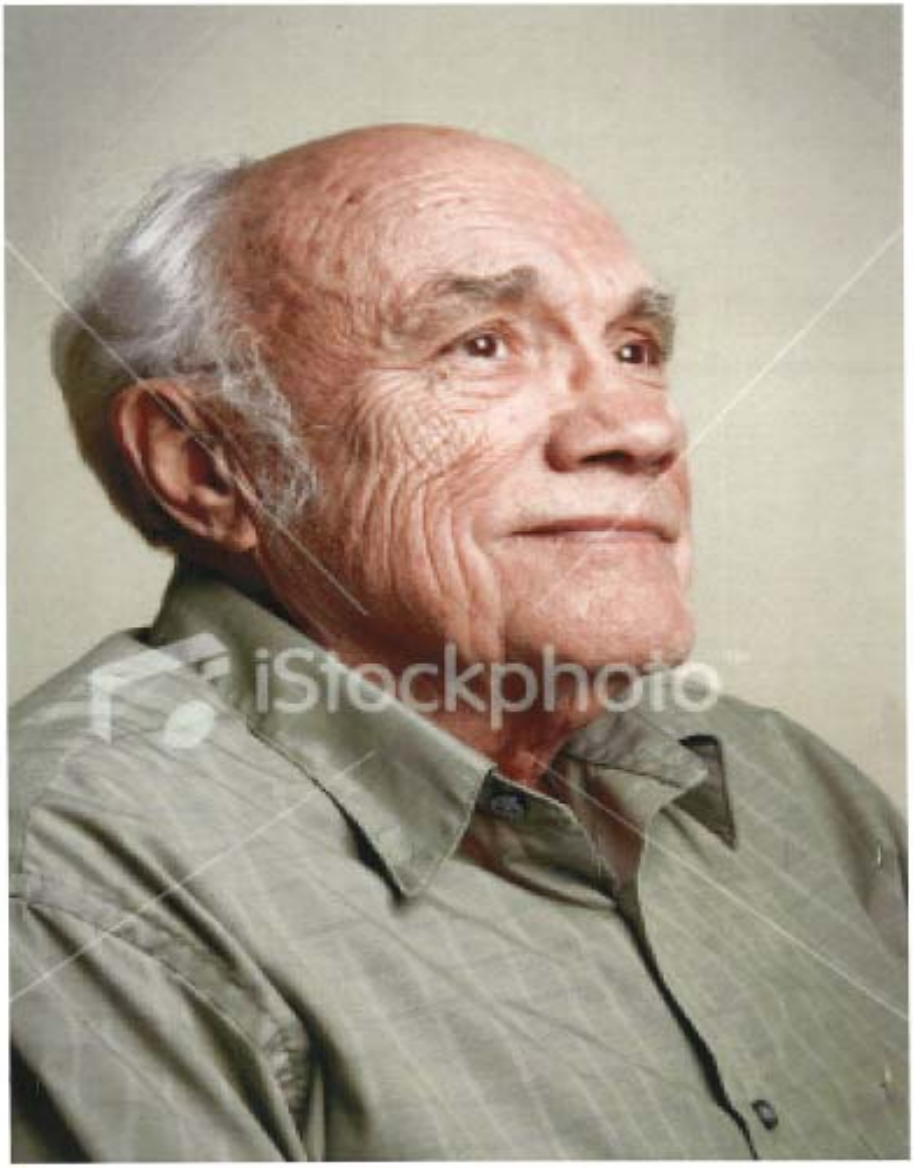
Appendix 4 Photographs used with indirect questions in the conversational interview guide for people with dementia

The photographs used were purchased from istock.com. For copyright reasons, the clean versions of the photographs are not included in the report.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Appendix 5 Self-completion questionnaire for carers

The questionnaire largely consists of core questions, with some additional questions relating to transport and meals. The relationship between individual questions and the components of person-centred care for people with dementia and carers respectively is summarised in Tables A18 and A19. Questions relating to facilitators and barriers to person-centred care are shown in Table A20.

Table A18 Components of person-centred care for people with dementia covered in the self-completion questionnaire for carers

Component of person-centred care	Relevant questions
Respecting individuality and values	11, 12, S2
Enhancing psychological well-being	14, 27, 28, 29
Promoting autonomy	15
Promoting a sense of shared responsibility	
Fostering social context & relationships	
Enhancing communication	
Meeting physical & personal needs	26, 30
Developing a therapeutic alliance	
Valuing expertise	

Table A19 Components of person-centred care for carers covered in the self-completion questionnaire for carers

Component of person-centred care	Relevant questions
Respecting individuality and values	3, 5
Enhancing psychological well-being	13, 20, 21, 22, 24
Promoting autonomy	18, 19, S4
Promoting a sense of shared responsibility	4, 6, 10, 17, S1
Fostering social context & relationships	1, 25
Enhancing communication	7, 12
Meeting physical & personal needs	23, S3, S5
Developing a therapeutic alliance	2
Valuing expertise	8

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Table A20 Facilitators and barriers covered in the self-completion questionnaire for carers

Facilitators and barriers	Relevant questions
Individuals	14
Person with dementia-carer dyad	
Organisational factors	3, 4, 9, 10, 12, 16, 17, S1, S2
Service ethos or culture	8

The core and supplementary questions are included below. Questions and instructions modified at a late stage are marked with an asterisk since these require further testing. Again, the front page of the questionnaire was designed for use in the present study, when the questionnaire was administered by researchers. The information and instructions would need to be tailored to the specific service and procedures for gathering and using information before being used elsewhere.

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Self completion questionnaires for carers: Core questions

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SOCIAL POLICY RESEARCH UNIT

INSTITUTE OF HEALTH AND SOCIETY
Newcastle University

Your views of <service name>

Working together to improve our service

We have sent you this questionnaire because your relative uses <service name>. We would like to know what you think about <service name>. We want to find out what is working well and what could be improved. Please be frank and honest; your answers will be treated in the strictest confidence. The results will be analysed by the University and a report will be produced for <service name>. If you use a number of different services, please just think about <service name> when you are completing the questionnaire.

When you have finished, please return the questionnaire to us in the enclosed pre-paid envelope within the next two weeks. If you have any queries or would like more information please contact: Claire Bamford, Tel: 0191 222 7047 email: c.h.bamford@ncl.ac.uk

To complete the questionnaire

- **Try not to take too long over each response – what comes to mind first is more likely to reflect what you believe**
- **Please answer all of the questions even if they seem repetitive or similar**
- **The questionnaire should take you no more than 15 minutes to complete**
- **Please circle the number which best describes your views or experiences**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The service provided is very reliable	1	(2)	3	4	5

1

The first questions are about your views and experiences of <service name>

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1	I get on well with staff providing the service	1	2	3	4	5
2	Staff have a good understanding of what I am going through	1	2	3	4	5
*3	The days/times the service is available are convenient	1	2	3	4	5
4	The service provided is very reliable	1	2	3	4	5
5	Staff do not show enough appreciation of my role as a carer	1	2	3	4	5
6	I would like to be more involved in making decisions about my relative's care at <service name>	1	2	3	4	5
7	I receive enough feedback about how my relative is getting on at the service	1	2	3	4	5
8	My views on how the service is run are taken seriously by staff	1	2	3	4	5
9	My relative sees too many staff from the service	1	2	3	4	5
10	Staff take my concerns about my relative seriously	1	2	3	4	5
11	Staff have a good understanding of my relative's needs	1	2	3	4	5
12	I have to remind staff about my relative's likes and dislikes	1	2	3	4	5
13	I worry about my relative while s/he is using the service	1	2	3	4	5
14	Staff are kind and caring towards my relative	1	2	3	4	5
15	Using this service helps my relative to stay at home	1	2	3	4	5
*16	I would like my relative to spend more time at the service	1	2	3	4	5
*17	The days/times my relative attends can be changed for special reasons	1	2	3	4	5

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The following questions are about how using <service name> affects your life

	Whilst my relative is using the respite service...*	A lot better	Slightly better	No different	Slightly worse	A lot worse
18	...the amount of control I have over my daily life is	1	2	3	4	5
19	...my ability to complete day to day chores is	1	2	3	4	5
20	...the opportunities to do things I enjoy are	1	2	3	4	5

	As a result of having a break ...*	A lot better	Slightly better	No different	Slightly worse	A lot worse
21	...my ability to cope with caring is	1	2	3	4	5
22	...my mood or spirits are	1	2	3	4	5
23	...my physical well-being is	1	2	3	4	5
24	...my overall quality of life is	1	2	3	4	5
25	...I enjoy the time I spend with my relative	1	2	3	4	5

If you live with your relative, please answer the following questions about how <service name> affects your relative. (If you do not live with your relative, please go to the questions on the next page)

		Always	Usually	Sometimes	Rarely	Never
26	My relative is physically well-cared for when using the service	1	2	3	4	5
27	My relative is reluctant to use the service	1	2	3	4	5
28	My relative is in a good mood after using the service	1	2	3	4	5
29	My relative is upset after using the service	1	2	3	4	5
*30	My relative seems to have had enough to eat at the service	1	2	3	4	5

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Finally, we would like to know your views on <service name>

31 The best thing about the service for **my relative** is:

32 The worst thing about the service for **my relative** is:

33 The best thing about the service for **me** is:

34 The worst thing about the service for **me** is:

35 How do you think this service could be improved?

Please use this space to add any other comments you would like to make about <service name>

Thank you for taking the time to complete the questionnaire
Please return it in the pre-paid envelope

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Self completion questionnaire for carers: Supplementary questions

For services where transport is provided:

		Always	Usually	Sometimes	Rarely	Never
S1	The transport arrangements for my relative run smoothly	1	2	3	4	5
*S2	The time my relative spends on the transport is too long	1	2	3	4	5

For services providing meals for the carer and person with dementia:

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
*S3	I enjoy all of the meals provided	1	2	3	4	5
*S4	There is enough choice at mealtimes	1	2	3	4	5
*S5	There was enough food throughout the day	1	2	3	4	5

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Appendix 6 Self-completion questionnaire for staff

A single version of the questionnaire was produced which is appropriate for all service types. The relationship between individual questions and the components of person-centred care is summarised in Table A21. Questions relating to facilitators and barriers to person-centred care are shown in Table A22.

Table A21 Components of person-centred care covered in the self-completion questionnaire for staff

Component of person-centred care	Relevant questions
Respecting individuality and values	3, 13, 22
Enhancing psychological well-being	1, 4
Promoting autonomy	11
Promoting a sense of shared responsibility	5, 14, 15, 19, 20, 23, 31
Fostering social context & relationships	21
Enhancing communication	26, 28
Meeting physical & personal needs	18
Developing a therapeutic alliance	
Valuing expertise	3

Table A22 Facilitators and barriers covered in the self-completion questionnaire for staff

Facilitators and barriers	Relevant questions
Individuals	
Person with dementia-carer dyad	
Organisational factors	2, 6, 7, 8, 9, 10
Service ethos or culture	5, 12, 16, 17, 25, 27, 28, 29, 30, 31, 32, 33, 34, 35

Questions modified at a late stage are marked with an asterisk since these require further testing. Again, the front page of the questionnaire was designed for use in the present study, when the questionnaire was administered by researchers. The information and instructions would need to be tailored to the specific service and procedures for gathering and using information before being used elsewhere.

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Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

THE UNIVERSITY of York
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INSTITUTE OF HEALTH AND SOCIETY
Newcastle University

Your views of respite care and short term breaks

You have been given this questionnaire because you work at <service name>. We are interested in your views about <service name>. We want to find out what is working well and what could be improved. Please be frank and honest; your answers will be treated in the strictest confidence. We hope that this will encourage you to say what you really think. Your answers will contribute to service review and development.

To complete the questionnaire:

- Please circle the number which best describes **your** views or experiences
- We would like you to think about what generally or usually happens
- Try not to take too long over each response – what comes to mind first is more likely to reflect what you believe
- Please answer all of the questions even if they seem repetitive or similar
- Some of the questions are concerned with your knowledge and skills – there are no right or wrong answers, we want to know what **you** think
- The questionnaire should take you about 10 minutes to complete

We understand that it can be difficult to answer some questions because things vary so much from day to day. We are interested in the overall picture, so you may find it helpful to think about the last 4 weeks as a whole when answering these questions.

When you have finished, please return the questionnaire to us in the enclosed prepaid envelope within the next two weeks. There will be a meeting to discuss the overall results in two to three months

If you have any queries or would like more information please contact:

Claire Bamford Senior Research Associate	0191 222 7047	c.h.bamford@ncl.ac.uk

Thank you very much for your time.

The following questions are about service organisation and delivery
Please circle the number that best describes your view

		Always	Usually	Sometimes	Rarely	Never
1.	My duties at work are satisfying	1	2	3	4	5
2.	I have enough time to get to know service users	1	2	3	4	5
3.	My opinions are considered when changes are made at work	1	2	3	4	5
4.	I feel drained as a result of work	1	2	3	4	5
5.	Communication between my manager and the rest of the staff team is good	1	2	3	4	5
6.	It is difficult to get everything done in the time available	1	2	3	4	5
7.	Our assessment and/or care planning documents help me to provide individualised care	1	2	3	4	5
8.	It is difficult to keep on top of the paperwork	1	2	3	4	5
9.	I have all the information I need to care for service users	1	2	3	4	5
10.	I feel pushed for time doing things with/for service users	1	2	3	4	5
11.	There are opportunities to try out new ideas at work	1	2	3	4	5
12.	There is enough time to discuss ways of improving the service	1	2	3	4	5
13.	I feel appreciated by my manager	1	2	3	4	5
14.	I can approach my manager if I have a problem at work	1	2	3	4	5
15.	There are opportunities to talk through difficult situations if needed	1	2	3	4	5
16.	My training needs are met	1	2	3	4	5
*17.	I have regular formal supervision	1	2	3	4	5
*18.	I worry that I'll be injured at work	1	2	3	4	5

The following questions are about how you and your colleagues work together as a team

		Always	Usually	Sometimes	Rarely	Never
19.	I feel I am part of a team	1	2	3	4	5
20.	My colleagues are approachable if I need advice	1	2	3	4	5
21.	There is a friendly atmosphere within our team	1	2	3	4	5
22.	I feel appreciated by my colleagues	1	2	3	4	5
23.	My colleagues and I work well together as a team	1	2	3	4	5
24.	Please use this space for any other comments you would like to make about team work					

The following questions are about both formal and informal supervision

	During supervision.....	Always	Usually	Sometimes	Rarely	Never
25.	...we identify appropriate training opportunities	1	2	3	4	5
26.	...I feel I am listened to	1	2	3	4	5
27.	...we discuss my career development	1	2	3	4	5
28.	...I am given useful feedback about how I am doing my job	1	2	3	4	5
29.	...I have enough time to reflect on how I do my job	1	2	3	4	5
30.	...we set and review goals	1	2	3	4	5
31.	...my supervisor understands my job well enough to help me resolve problems	1	2	3	4	5
32.	Please use this space for any other comments you would like to make about supervision					

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What do you think are the <u>three</u> most important areas in which you need training or updating?

33. ***Please read the list below, then tick what you think are the three most important areas in which you need training or updating***

Person-centred care for people with dementia	☐
Promoting well-being and independence in people with dementia	☐
Activities and occupation for people with dementia	☐
Enabling communication with people with dementia	☐
Causes, signs and symptoms of dementia	☐
Reminiscence and life history work	☐
Valuing cultural diversity	☐
Working with younger people with dementia	☐
Managing challenging behaviour	☐
Developing positive relationships with carers and families	☐
Managing stress	☐
Working effectively as part of a team	☐
Other *(Please write below)*	☐

Please tick 3 only

What do you think are the <u>three</u> most important aims of <service name>?

34. ***Please read the list below, then tick what you think are the three most important aims***

- Enable people with dementia to stay at home as long as possible ☐
- Provide a break for the carer ☐
- Provide a break for the person with dementia ☐
- Enable person with dementia to maintain links with the local community ☐
- Maintain skills and independence of person with dementia ☐
- Improve psychological well-being of person with dementia ☐
- Provide stimulation for person with dementia ☐
- Provide advice and support for carers ☐
- Prepare the person with dementia and carer for long-term care ☐
- Other (*Please write below*) ☐

Please tick **3** only

What do you think are the <u>three</u> most important aspects of providing care for people with dementia and their carers?

35. ***Please read the list below, then tick what you think are the three most important aspects of providing care for people with dementia and their carers***

- Knowing the life history of the person with dementia ☐
- Providing a range of activities ☐
- Treating people with dementia with dignity and respect ☐
- Treating carers with dignity and respect ☐
- 'Doing with', rather than 'doing to' ☐
- Looking at the world from the perspective of the person with dementia ☐
- Individualised assessment and care ☐
- Valuing the staff team ☐
- Other (*Please write below*) ☐

Please tick **3** only

We would like your ideas for improving <service name>

36. How could the service provided to people with dementia be improved?

37. How could the service provided to carers be improved?

38. **Please use this space to add any other comments you would like to make about <service name>**

*39. **Finally, please tick the box that best describes your role**

- Manager ☐
- Team Leader/Supervisor ☐
- CPN or other Nurse ☐
- Care/Support Worker ☐
- Volunteer ☐
- Other (please specify) ☐

Thank you for taking the time to complete the questionnaire
Please return it in the pre-paid envelope

Appendix 7 Vignettes for staff discussion

The vignettes were not designed to relate to specific components of person-centred care, but rather to encourage discussion of such care. A key intended outcome of the discussion was to highlight issues relating to service culture and ethos which could impact on the delivery of person-centred care. The document containing the vignettes is reproduced below.

THE UNIVERSITY of York
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SOCIAL POLICY RESEARCH UNIT

INSTITUTE OF HEALTH AND SOCIETY
Newcastle University

Your views of respite care and short term breaks

Scenarios for discussion by the staff team

Introduction and instructions

The term 'person-centred care' is often used in describing services for people with dementia. Staff know they 'ought' to be providing person-centred care, but many staff do not know exactly what it means or how to provide it. This is not surprising since there is no agreed definition of person-centred care. Most people would agree that one aspect of person-centred care involves seeing things from other people's point of view.

We suggest that you work together in a small group (4-6 people) and allow about 45 to 60 minutes. The groups need to be facilitated to make sure that everyone has an opportunity to contribute and to keep the discussion on track. This is your opportunity to be creative, you should feel free to explore new ideas or new ways of doing things; not all changes necessarily involve financial costs.

This booklet has two parts. The first part uses fictional scenarios to illustrate challenges that can arise in providing person-centred care. Each one of these will probably take about 15 minutes, and you may just want to discuss one. Each scenario describes a fictional service user and the issues(s) in providing care. The scenario is followed by questions to help structure your discussion and a 'model' answer. The model answers do not include all possible answers and as a staff group you will probably have more ideas and may disagree with the answers. We have deliberately not included a lot of detailed information about each scenario. We hope this will encourage a more wide-ranging discussion. If you need more information before discussing the questions, start by identifying what else you need to know and how you could use this information. In the second part of the booklet, you are asked to apply the same structured questions to one or more people who are currently using your service.

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Scenario 1 – Jack and Susan

The Beeches is a day centre specifically for people with dementia.

- Jack is a 68 year old widower who lives alone. Until a few years ago he had been a keen gardener; winning several prizes for the leeks he grew on his allotment. Jack was diagnosed with Alzheimer's disease a year ago. He no longer keeps in contact with his remaining friends from the allotment. Carers help him with cooking, shopping and washing. His daughter, Susan, has taken responsibility for Jack's financial affairs as he was no longer able to manage to pay his bills.

- Susan is a single parent who lives 40 miles away with her 3 young children. She feels upset that her dad has changed and that she now has to look after him. Susan feels guilty that she doesn't visit him more often, but it is difficult to find the time and the money.

- Jack's social worker felt that he was socially isolated and would benefit from day care at the Beeches. Jack settles in well as there are some other men there who have similar interests. Staff at The Beeches have organised to take the group of men out to a National Trust garden for the day. They have calculated that for transport, lunch and admission it will cost £15 per person. They approach Susan for the money who says that it would be pointless as Jack won't remember going and it will disrupt his routine.

Questions

- Put yourself in Jack's position – what are the important issues for him?

- Put yourself in Susan's position – what are the important issues for her?

- Put yourself in the staff's position – what are the important issues for them?

- What could the staff do to help the situation?

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Model Answer Scenario 1

Jack's Position

Jack has become socially isolated; he has lost his friends from the allotment. He loves gardening, but is no longer doing this. We don't know how Jack feels about this trip; although he may want to go, he might be fearful of going somewhere different. Jack may be upset by the conflict with his daughter. He does seem to have the money to go on the trip if he wants to.

Susan's Position

It is not clear what Susan's position is. Her view of what constitutes Jack's quality of life is quite negative. She is possibly not thinking of her Dad as the person he once was - he's different to her now. What knowledge does she have of dementia? What is the frequency and quality of her contacts with the day centre? What is the detail of her managing her Dad's affairs - does she have Lasting Power of Attorney? Is she short of money herself? Could there be issues of financial abuse? Would the money be better spent on allowing to Jack to spend time with his grandchildren?

Staff Position

They could feel caught in the middle of Jack and Susan. They could feel disappointed that he's not being included. They could feel that there is no point trying to provide person-centred care because their efforts are thwarted by relatives. Person centred care can sometimes be more expensive.

What could be done?

- ***Provide Jack with choices***

Ask Jack what he wants to do. Explore other options, for example, a visit to his allotment either with day care staff or other support services available locally (for example, befriending or a one-to-one support service). This would be free and could give Jack the opportunity to meet up with old friends. Jack may be able to re-establish friendships at the allotments if he is supported to visit. This may be a way of preventing isolation, especially as Susan does not live near by. Opportunities for gardening in the day care centre could also be explored. This might offer low cost activities for Jack and other persons attending the centre. Even if there is no garden, some activities could be conducted indoors, for example, planting bulbs, growing herbs or sprouting seeds such as cress.

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- ***Explore alternative sources of funding***

Look at whether funding is available from other sources so there is no extra outlay for activities and outings. Opportunities for fundraising may also generate new activities at the day centre and may be a way of involving and getting to know carers.

- ***Providing support for carers***

Support for Susan could take the form of discussing and acknowledging her fears and concerns. It may be useful for staff to explain to Susan that it is about the quality of the moment, not whether Jack can remember it or not. Providing information, either through discussion or the provision of leaflets, may increase Susan's understanding of the condition. Staff may also be able to provide Susan with practical advice or further information on financial matters and access to any relevant benefits.

- ***Improving communication with carers***

Day centre staff may not have the opportunity to see relatives on a regular basis, making it difficult to establish relationships and discuss issues. Although Susan lives some distance away and has a young family to care for, telephone contact or text messaging may be a useful means of communication, with regular updates from staff. Susan could be invited to visit the day centre at a time which is convenient to her so that she can meet staff and find out more about the service. Staff may want to review the way in which service users and carers are introduced to the day centre. An initial step might be to collect information from service users and carers about their first contacts with the day centre and exploring how the process could be improved.

- ***Joint working with other services***

Consider the involvement of an independent advocate if necessary. This may relieve the pressure on staff to negotiate between Jack and Susan. Although this could have an unpredictable effect on the family dynamic, it may be a useful strategy for meeting the needs of the person with dementia, their carer and perhaps other family members. If Susan does not have Lasting Power of Attorney then the best strategy to help Jack to manage his finances could be explored.

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Scenario 2 – Bob and Doris

Greenhills is a nursing/residential home with two dedicated respite beds.

- Bob has been married to Doris for 52 years. Whereas Doris has always enjoyed the company of others, being an active participant in the local church, Bob has always preferred his own company, being quite happy to potter at home until Doris returned. Since Bob had a stroke 2 years ago he's been increasingly muddled and anxious. He doesn't like to be on his own now and follows Doris around the house. Bob was found by a neighbour wandering in the street six months ago when Doris was out at church, so she no longer leaves him alone. Bob gets up several times each night and is frequently up for the day at 4am.
- Doris is tired and in poor health herself. She feels she can no longer manage to look after Bob at home. She is reluctant for him to go into care but agrees that a week in respite at Greenhills might help her to regain her strength.
- When Bob gets to Greenhills he sits alone near the door and repeatedly asks when he will be going home. He doesn't want to join in groups and doesn't see why he's there. "They're all old and mad" he says.

Questions

- Put yourself in Bob's position – what are the important issues for him?
- Put yourself in Doris' position – what are the important issues for her?
- Put yourself in the staff's position – what are the important issues for them?
- What could the staff do to help the situation?

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Model Answer Scenario 2

Bob's Position

Bob is probably feeling lost and bewildered. He may not understand why he is not at home or what has happened to Doris. He may be anxious or frightened about what will happen in the future. He may feel that Doris doesn't love him anymore and that she has abandoned him in a strange place or that he has done something wrong. He may have forgotten about Doris altogether, his memories going back to childhood, with the result that he feels abandoned.

Doris' Position

Doris may be feeling guilty about using respite care and worried about how Bob is getting on. A break of one week is unlikely to be long enough for Doris to recharge her batteries. She may be feeling lonely without Bob, particularly as she has lost touch with her friends from church. She may be worried about how she will manage when Bob comes home again.

Staff Position

Staff may be feeling frustrated at looking after Bob when he is obviously unhappy. They may feel powerless to comfort him. They may feel that they don't have enough time to spend with him.

What could be done?

Find out more about Bob – what sorts of things he likes doing, what kind of job he did, how he and Doris used to spend their time together. Try to find someone in the home (either a member of staff, another resident or a volunteer) with something in common with Bob. Consider whether there are any staff who may be able to connect with Bob and provide him with a sense of security or reassurance.

What could be done in the future to address these problems?

- ***Improve preparation for respite care.***

This could include more detailed assessment to learn more about Bob and how he likes to spend his time. Activities which are likely to interest him could then be arranged during his respite stay. A buddy system with another resident with similar background or interests may help Bob to feel more settled whilst at respite.

Doris may also need support to prepare for respite. It may be helpful to ask about church contacts and whether she would like to see them whilst Bob is away. Doris and Bob could have been invited for lunch a couple of times at the home prior to the respite stay so that they would be more familiar with the routines, building, staff and other residents. A greater emphasis on working in partnership with Doris may have allayed her anxieties about long-term care and helped her see respite as a way of trying to keep Bob at home for as long as possible. Staff need to gain Doris'

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trust and gradually build up a relationship with her if regular respite care is to be successful. Staff need to explain that different carers chose different levels of contact during respite care, and that whatever level of contact Doris wants will be respected by staff.

- ***Offer a wider range of services***

It is not clear how much choice was given to Bob and Doris about the respite offered. Alternative models of respite, such as one to one support at home, may have suited the couple better and provided a more gentle introduction to service use. Other services and organisations may be able to support Bob and Doris in the community (e.g. befriending). The possibility of direct payments could be explored, since this could perhaps be used to support Doris with domestic chores in view of her own health problems.

- ***Provide staff training***

Consider how well staff understand dementia. Consider the activities on offer in the home and whether more physical activities might be needed for people on respite care who may be fitter than other residents.

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Scenario 3 - Gladys and Lisa

Holly Court is a day centre for frail older people.

Gladys is a 74 year old widow with mild to moderate dementia. She has been attending day care for 3 months. Staff at Holly Court are becoming increasingly frustrated with the effect of Gladys' behaviour on other clients. Every afternoon she gathers some of the other ladies together and they search for a bus stop. Although some ladies follow her, others laugh at her and make nasty comments. Staff tell Gladys many times a day that she is at a day centre. Gladys becomes aggressive when told that she won't be going on a bus. When staff telephone Gladys' daughter Lisa they find out that after her retirement Gladys remained an active, sociable lady who used to organise coach trips for the Stroke Association. Lisa says that she gave the manager this information when she came to assess Gladys for day care.

Questions

- Put yourself in Gladys' position – what are the important issues for her?
- Put yourself in Lisa's position – what are the important issues for her?
- Put yourself in the staff's position – what are the important issues for them?
- What could staff do to help the situation?

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Model answer for scenario 3

Gladys' position

In dementia most recent memories are lost first (like redundancies it is last in, first out), this takes the person back to an earlier part of their life. Because Gladys has dementia she believes that she is still organising the coach tours. She believes that the trip won't go ahead if she can't gather the ladies together at the bus stop. She becomes aggressive because staff are preventing her from doing this.

Lisa's position

Lisa knows that her mother would never have wanted to be a burden to anyone. Lisa feels upset for Gladys that she is seen as a problem, not as the kind, caring person she once was. She feels guilty about not being able to look after her mother and now she is also anxious that staff will not be able to cope with her mother and will ask her to leave the Holly Court. Lisa is irritated about being phoned at work – the whole point of day care for Lisa is to enable her to get on with her job without being interrupted. Lisa has concerns about the competence of staff at the day centre, particularly since she had already completed a time-consuming assessment with the manager.

Staff position

Staff are beginning to dread the days when Gladys is attending. Some staff are fed up with constantly repeating the same information. The member of staff who phoned Lisa is embarrassed that the information given to the manager had not been passed on.

What could be done?

- ***Value Gladys' role as an organiser***

People with dementia often lack opportunities to contribute their skills and experience. The transition from being a person who looks after others to being looked after oneself is often difficult. One possibility might be to identify roles that Gladys could take on in the day centre, perhaps specifically in the afternoon at around the time she tends to try to organise everyone to go to the bus stop. Could Gladys help with getting people ready to go home at the end of the day?

- ***Occupy Gladys with another enjoyable activity***

Engaging Gladys in another activity in the afternoons may help to avoid the situation where she is trying to organise other people.

- ***Improve communication within the day centre***

Useful information from the assessment was available to the manager but not to frontline staff. This highlights the importance of **using**, as well as collecting, information. The fact that staff phoned Lisa without first discussing the situation with the manager suggests that there are limited opportunities for supervision or for discussing problems at the day centre.

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- ***Increase support for staff***

Are staff becoming frustrated with Gladys because they are struggling with work generally? Staff may feel unsupported by managers or that they feel they lack the skills to deal with the situation. Staff may never have had an induction or training. Consider how well staff understand dementia – some basic introductory training might be provided for all staff. As Gladys is unlikely to be the only person with dementia attending Holly Court, it might be worth training two or three members of staff as dementia experts who could then act as a resource for other members of staff. Ensure that there are good links with local dementia services so that people with dementia who need more specialist care can move smoothly between services. Even with adequate training, staff require ongoing support. Consider whether staff are receiving sufficient supervision and have regular opportunities to meet informally to provide mutual support.

- ***Reassure Lisa***

Even if a review meeting has recently been held to assess how Gladys is getting on at Holly Court, consider arranging a brief meeting with Lisa. If possible, this should be at a time which fits around her work commitments. Apologise to Lisa for the lack of communication of information and explain how this will be addressed in the future. Explore Lisa's concerns over whether Holly Court is the right place for her mother and explain the links between general and specialist services for people with dementia, so that Lisa knows what to expect if her mother needs to move to a different service.

- ***Manage relationships between clients***

Nasty comments from other clients may upset Gladys even if she doesn't seem to react to them. It is therefore important to tackle this issue. It may be possible with certain clients to discuss their remarks, but at other times the solution may involve separating people within the service.

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Applying this approach to everyday practice

1. Identify a service user and/or carer with whom you have difficulties in providing person-centred care. In some services you may not all know the same service users and carers. In this situation, one person should chose a service user or carer and describe the individual, their circumstances and the difficulties experienced to the rest of the group. You might like to think about:

    - The last service user who left the service
    - A service user with whom staff find it difficult to establish rapport
    - A service user who does not seem to 'fit in' with other people using the service
    - A carer with whom you have found it difficult to establish a relationship

2. Work through the same questions:

    - Put yourself in the service user's position – what are the important issues for him/her?
    - Put yourself in the carer's position – what are the important issues for him/her?
    - Explore the important issues for different members of staff
    - What information do you need in order to try to help the situation? How might you find this out?
    - What could you do to help the situation?
    - What could you have done at an earlier stage to either avoid or minimise the current difficulties?
    - What can you learn from this exercise to improve the service in the future?

If the situation you are discussing relates to a personality clash or difficulties with the person with dementia fitting in or settling into the service, you may want to consider the additional questions overleaf.

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Additional questions relating to personality clashes

- How might each person feel?
- How might you feel in this situation?
- How have you felt in similar situations?
- What would make you feel better in this situation?
- What might explain how each person is feeling and behaving?
- What other factors could contribute to each person's feelings and behaviours?
- How might the characteristics of each person affect the situation (e.g. age, gender, ethnic group)?

Additional questions for situations where the person with dementia does not fit in or settle into the service

- How do we know when service users do not 'fit' or 'settle' in the service?
- What are the consequences when service users do not 'fit' or 'settle' (for the individual, other service users, carers and staff)?
- Are there particular times of day or events when the service user is more settled than at others?
    - What is happening at these times?
    - How are staff and other service users behaving or interacting at these times?
    - How can we use this information to help the service user at other times?
- Are there settings or situations in which the service user is more settled? (i.e. outside the service)
    - What is happening at these times?
    - Who else is present and how are they behaving or interacting at these times?
    - How can we use this information to help the service user at other times?

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