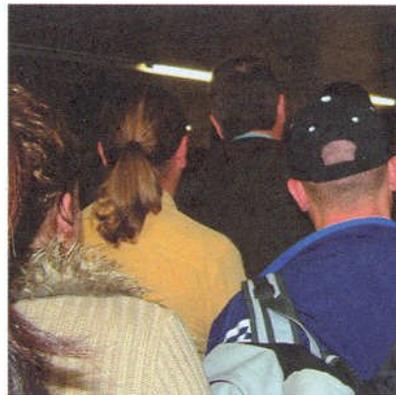
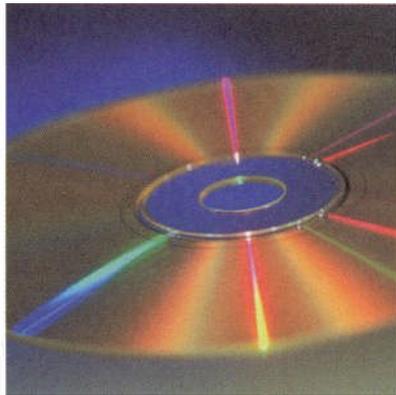


Empirical Research Methodology for 'Procare' Research Version 3



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**Centre for Health Services Studies
University of Kent**

June 2003

PROCARE

Providing integrated health and social care for older persons
| issues, problems and solutions |

European Centre for Social Welfare Policy and Research (co-ordinator) | Danish National Institute of Social Research (SFI) | Research Society for Gerontology - Institute of Gerontology at the University of Dortmund | National Research and Development Centre for Welfare and Health (STAKES) | Union nationale interfédérale des œuvres et organismes privés sanitaires et sociaux (Uniopss) | National Centre for Social Research - Institute of Social Policy (EKKE) | emme&erre s.p.a. | Studio Come s.r.l. | Dr. Hilda Verwey-Jonker Institute | University of Kent at Canterbury - Centre for Health Service Studies (CHSS)



Empirical Research Methodology for 'Procure' Research Version 3

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Canterbury**

UK

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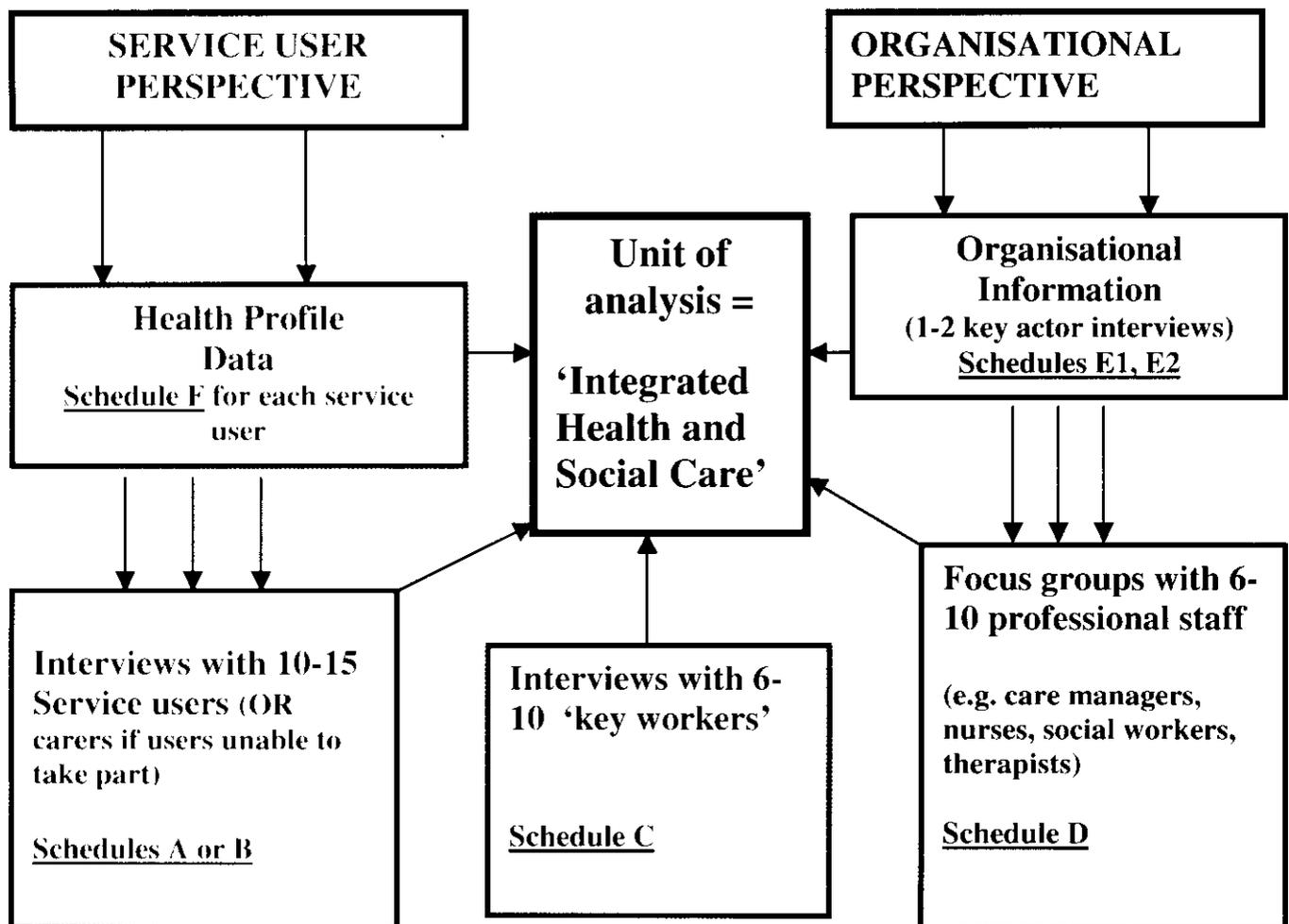
'Procare': Methods Paper and Instrumentation

Purpose

This paper provides a plan of investigation to reveal the nature and practice of two integrated care services (models) in each of the nine partner countries, from the organisational and user perspective. The objectives of the investigation will be to:

- Describe how services work to provide integrated health and social care,
- Explore the experiences of integrated care from the user and carer perspective,
- Identify the impediments to effective working and how to overcome them
- Assess the extent to which these services are person-centred
- Use this data to identify quality indicators for integrated care for use in policy making and service planning

Figure 1: Case study: 'Unit of Analysis' and Multiple Data Sources



Research Design

Given the European scope of the 'Procare' programme, it is important to ensure a valid and consistent approach across diverse contexts and environments, therefore the provision of a suitable research design is paramount. The design needs to be both robust, to enable the maximum collection of data with minimum resources, and flexible to incorporate and be applicable to a wide range of diverse settings. Given the exploratory and innovative nature of the work, experimental designs such as randomised controlled trials or large sample surveys are not appropriate, due to the different contexts and diversity of data required.

Case study design would be appropriate as this design can bring together different forms of data and permit the study of both the objective characteristics of systems and subjective experiences across contrasting areas (Yin 1994). A case study would facilitate the capturing and interpreting of systems of care through the triangulation of multiple data sources, and the use of exploratory methods that are sensitive and able to reveal and explain the complexities within this area of health and social care (Pope and Mays 2000). Using Yin's classification, the design can be applied to the requirements of this part of the study in the following way:

- Each project (model) that is selected for analysis becomes a case study. With full partner participation, there will be two case studies per country and 18 case studies in all. This becomes a multiple case study design.
- Case studies have a central unit of analysis, which is the focus of the study. Our unit of analysis will be 'integrated health and social care'.
- In order to fully investigate the units of analysis in relation to purpose of the study, different types of qualitative and quantitative data will be brought together to generate insight into integrated care (see Figure 1 for illustration). As far as possible, these will be the same for each case, in order to permit meaningful comparison and 'replication logic' (Yin 1994). This serves to strengthen developing theories across the case studies.

Criteria for Selection of Sites

Each participating country has already included within their respective reports a discussion of models and exemplars. Each partner will be select two models and identify sites in which these models are used. It is anticipated that such sites will be examples of innovative practice. Criteria for selection will be:

- Established (and providing service) for six months or more
- An organisational goal of providing integrated health and social care for older people
- Existing evidence that there is integrated/collaborative working between health and social care professionals (i.e. at least one interface between health and social care provision)
- Existing systems within the organisation to gather information about client group and service uptake
- Organisations of any size can be selected, but there should be sufficient numbers of staff and clients to provide 5-10 interviews from each group, having allowed for a number who may not wish to take part (approximately 30-50% refusal rate may be considered usual in this type of research).

Please note

There are further selection criteria relating to the selection of service users/carers on p.9, and key workers on p.10.

Methodological Approaches

There are two main approaches to data gathering within the 'Procare' empirical framework. These are:

- **Individual interviews**, where an individual's experiences, feelings and attitudes are sought.
- **Focus groups**, where multiple views are sought, together with some insight into the interpersonal processes that may be operating within an organisation (Gibbs 2003). For a helpful and practical guide to focus groups, see: <http://www.soc.surrey.ac.uk/sru/SRU19.html>

In addition, a small amount of data will be gathered using structured schedules. These are:

- **Schedule E2**, data for which may be gathered from a number of individuals throughout the organisation and
- **Schedule F**, items 1-4 of which should be completed for every service user respondent. If a carer is taking part on behalf of a service user, Schedule F should be completed with the carer's help, but the information should relate to the older person, not the carer. Items 5 and 6 may be gathered if country teams would find this useful when analysing data or writing research reports.

Pilot Study

Each participating country should conduct a small pilot study (in one model only), to test the data collection schedules. Once access to a model has been negotiated:

- One key-worker should be selected and interviewed using Schedule C
- One manager or professionally qualified member of staff should be interviewed (or talked through) Schedule D
- One client (or carer) should be interviewed (or talked through) Schedule A or B.

The reasons for doing this are to ensure that the questions make sense to researchers, service workers, clients and carers when used in the model setting, to allow researchers to familiarise themselves with any equipment and with the logic and progression of the schedules, and to help estimate how long interviews/focus groups might take for project planning. Any problems with translating key terms or questions can be fed back to the co-ordinators or the UK team, and the goal would then be to reach a consensus interpretation and then circulate this to other partners.

The aims of this exercise are therefore related to practical issues rather than robust data-gathering, and so it is important that respondents who take part in pilot studies should not be involved in the main study, and that any data gathered during the pilot study is not included in the main study data analysis. There is no need to do this in both model projects, because the initial pilot study should iron out any language or key concept problems, and there is enough

flexibility within the schedules to allow for some adaptation between different exemplar projects.

Triangulation

The study design also has a number of features that will enhance rigour, important when conducting research of this nature. Construct validity can be enhanced in case study research through the triangulation of methods, that is, the collection of a variety of different types of data so that data converges around emerging theories. In particular, the method of data analysis uses a 'pattern-matching' approach that permits the blending of different types and levels of data from all the cases into an explanatory model. The external validity of case study research is supported through the use of a number of tactics, in particular, the concept of analytical generalisation, which involves generalising to established theory (Yin 1994; Keen and Packwood 2000).

Challenges to study rigour

The 'Procure' partners have identified some challenges that are presented by this use of case study design in a pan-European study. These include:

- The quality of the data may be variable between sites, depending on the skills and experience of individual researchers in qualitative methodology
- There are likely to be difficulties in translating key concepts and themes between different languages and cultural contexts
- The diversity of proposed 'models' reduces the likelihood of standardised interviews/focus groups being held in all countries.
- The method of data analysis has yet to be agreed
- The timescale is not feasible for all countries, due to vagaries such as the need to obtain formal ethical approval, or the closure of some services over summer vacations.

Following discussion on these points, it was proposed that although a degree of flexibility between sites was essential, there would be:

- Consensus on the 'key questions' in interview/focus group schedules (following work groups at Canterbury conference with input from all partners)
- An opportunity for translation of schedules will be quickly available so that any problems are identified before data collection commences
- A pilot study should take place in each country to test the data collection tools, before main data collection commences.
- There will be close collaboration between the UK and German teams, who are responsible for methodological design and data analysis tools respectively

Linking the Methodology to the Conceptual Theory: A Framework for Exploring The Quality of Integrated Health and Social Care

Whilst a diverse range of integrated care schemes may be investigated across the participating 'Procare' countries, a unifying theme is exploring the quality of care provided by these model projects to their users. As Ex and Gorter (2002) comment in the Netherlands National Report,

“when the requests and needs that the client may experience in various areas are met, then that constitutes integrated care “ (p. 21)

In the 'Procare Theoretical and Conceptual Issues' paper (Alaszewski 2003), Donabedian's (1980) framework for measuring the quality of care is proposed as a useful resource for investigating models of integrated care. This framework identifies three elements within organised care services: structure, process and outcome. The framework has been incorporated within the methodological design, mainly to assist with linking the theoretical and conceptual elements during the development and analysis of the empirical work. However, the different elements are likely to be merged in the 'real world' of the models being studied, and as a result it may not be helpful to think of these elements as separate entities in the design methodology. For example, the study design does not follow a linear 'structure-process-outcome' model, but rather considers how different sources may provide a mixture of information about these different elements of service provision.

Structure

'Structure' focuses on the resources available to organisations and care providers, for example funds, buildings or expertise. It can also refer to issues such as physical access to buildings, the availability of 'points of entry to care' and when the service is provided, i.e. 24 hour, weekend cover, holiday cover (Donabedian 1980 p.95). Within the proposed methodology, the organisational structure is explored by key actor interviews and by collating 'baseline organisational data' for each model studied (Schedules E1 and E2). Structure will also be revealed by organisational staff focus groups and key worker interviews, and there may be different accounts of organisational structure from managers, staff, key workers and users/carers.

Process

The 'process' of care involves the relationship between staff and users, and the approach taken to care delivery. This incorporates many features of care provision, including uptake of services, needs assessment, care planning, respect for user autonomy, the number of staff involved, methods of referral and follow up.

The intention during data gathering is to discover how care is actually provided by the model being investigated, and how it is evaluated by the organisation both for efficacy and for user satisfaction. This aspect is explored by holding focus groups within the organisation (Schedule D), by interviews with staff that provide 'hands-on' care (Schedule C) and by cross-validation of client and staff perceptions of the organisational process.

Outcome

Within the 'Procare' empirical study, the 'outcomes' for users and carers are the factors which service users/carers consider important, or find beneficial within an integrated health and social care approach. Such factors provide qualitative evidence that an integrated provision of health and social care has enhanced the users' experience by facilitating appropriate and individualised (person centred) care. The data gathered during this study may then be used to develop evidence based quality

indicators that specifically reflect the phenomenon of integrated health and social care. This data will be obtained by conducting interviews with service users or, if the users themselves are unable to participate, by talking to their family or informal carers (Schedules A and B).

This 'person centred' or 'holistic' approach was adopted to reflect the model of older people's health that was commonly identified within the policy agendas of participating countries. Other types of outcome which are commonly researched include improved physical or functional well-being, or changes to use of acute 'inpatient' services, but these factors require long-term quantitative projects that are beyond the resources or remit of the 'Procare' project. However, as the following quote indicates, exploration of 'person-centred' outcomes is supported and valued within Donabedian's (1980) framework:

“...the attributes that are part of the quality of life - for example the maintenance of autonomy and self-respect - are also attributes of a desirable client-practitioner relationship and, in this way, become part of the definition of quality” (Donabedian p.30).

Data Sources: Sampling and Data Collection

This will be described and rationalised according to firstly the user/carer perspective, secondly the organisational perspective and thirdly the 'key worker' perspective. Figures 2, 3 and 4 are flow charts indicating the pathways through the data collection process for each of the perspectives. Interview schedules for the collection of user and key worker views have been attached. Their development reflects areas that are key to integrated care, as identified in the National Reports, the theoretical paper and subsequent discussion at conference.

An important feature of the study will be close networking with the appropriate staff at the sites, which will be crucial to the identification of key informants for organisational data, and successful recruitment of people to the interviews.

1. User and Carer Perspective

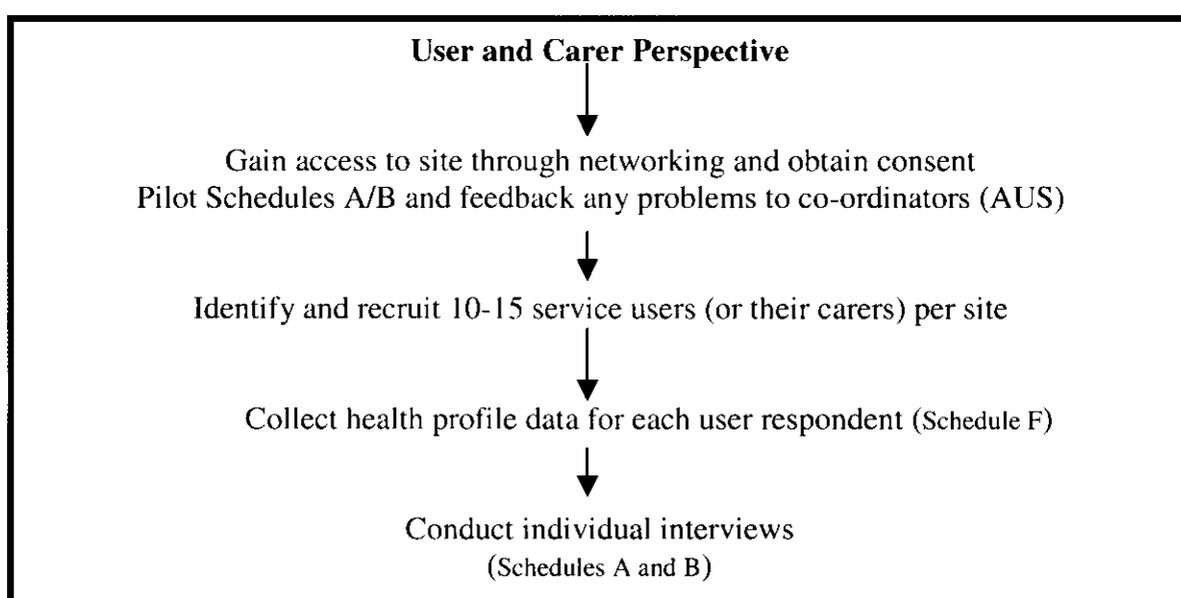


Figure 2: Data Collection flow chart for User and Carer Perspective per Site

The purpose of interviewing users (or carers) and key-workers is to discover their impressions of the integrated service that is being provided by the model, and to identify whether this experience suggests that 'integrated', 'co-ordinated' or 'seamless' care has been provided. This data is intended to provide information mainly about the 'outcome' component of Donabedian's (1980) framework, i.e. whether the client has experienced a holistic and client-centred service. It is also anticipated that data about 'process' (i.e. how the service operates to fulfil its goals) will be gained both from clients and their carers.

User (or carer) data will be collected through a semi-structured interview schedule which enables in-depth exploration of issues within a key area and, with the permission of participants, all interviews will be tape recorded to maximise richness of data (Fontana and Frey 1994). In addition, it will be important to use field notes to record impressions gained during the discussions. These may be of a contextual or interpersonal nature. This will increase the richness of data and contribute towards the explanatory models. Questions will focus on the experience of receiving integrated care, the ability of the service to meet their personal health and social care requirements, and what improvements could be made (see Schedules A [users] and B [carers]). It is suggested that the views of carers should be separate from those

receiving the service where possible. This in order to obtain honest and candid opinions of integrated care that in the presence of the user may not otherwise be expressed (Burnside et al 1998).

Interviews with Users and Carers

The sampling framework will be purposeful, and criteria for selection are proposed as follows:

- Service users (aged 65+) who are currently in receipt of or who have been in receipt of the service within the last month (to aid recall)
- Service users who have received services from the chosen model for at least a month (to provide rich data based on experiences of receiving service over time).
- Service users who are able to communicate and establish point of view
- Where service users are unable to take part (due to sensory, cognitive or physical impairment) their carers may be invited to participate on their behalf. For the purposes of this study, only informal carers (see Glossary) should be included here – formal (paid) carers would be key-workers and could be interviewed using schedule 'C'.

Given the data collection time span, the suggested sample number of users and carers per case study site is 10-15, making a total of between 20-30 across both sites. Ideally, there should be diversity amongst respondents – for example, differences in age or level of dependency. This data will be identified within the 'Health Profile' (Schedule F). Whilst the suggested sample size is fairly small, the research is not designed to identify a representative sample, but rather a purposeful sample that are able to provide data which will support (or refute) the theories and concepts identified in the National Reports and summarized in the Theoretical Paper (Alaszewski 2003). Within this methodological approach, data gathering will ideally end when the point of 'data saturation' is reached (Glaser and Strauss 1967) – i.e. when interviews or focus groups are producing more of the same information, rather than when a specific number of interviews/focus groups have been completed. This also allows or flexibility between models as the type of model studied may influence the number of interviews/focus groups that will be required to reach this point.

Health Profile Data

Data that will identify some demographic, health and social characteristics of the sample will be collected, in order to obtain a basic profile of those participating. As the samples will be purposeful, there will be an inherent bias induced by self-selection; therefore cross case comparison of detailed health and social measures will not be meaningful to the study. Some consistency of approach will however be desirable. This data can be collected using Schedule F, and it is suggested that all countries should collect questions 1-4 for each **user respondent**, and that questions 5 and 6 could be used if individual countries wish to have an idea of the level of care dependency of respondents to support their analysis of the model in the context of their country's policy.

Access to respondents

Each country should negotiate access the sample in accordance with their own code of conduct, following clearance from ethical committees (where applicable).

Identifying Respondents

During the data analysis and dissemination stages, it will be important to identify the role and source of the respondent within the data. It is normal to protect the identity

of respondents in research findings, and so each country should come up with a method of listing respondents and their roles (e.g. user, carer, nurse, administrator), linking these to an anonymous system. For example:

Date	Method	Name	Role	Code
17.07.03	Focus group	John Smith	Nurse	A1
18.07.03	Interview	H.Heinzen	User	B1
19.07.03	Interview	J. Jansson	Carer	C1

Summary of service user/carers data gathering process:

1. For each model, identify potential respondents and approach (via gatekeeper/key-worker or according to local ethical guidelines):
 - 10-15 service users (only approach carers if users are unable to take part – for example due to dementia)
2. Complete Schedule 'F', items 1 to 4 for all user respondents – if a carer is acting on behalf of a user, they should be asked for this data about the user- the user being the intended recipient of the service, even if the service benefits the carer too. Reach local (country) agreement on items 5 and 6.
3. Conduct and tape-record individual interviews using Schedule A or B as appropriate. Separate carers from users where possible/practical for interviews.
4. Ensure respondents can be linked to data gathered – see 'identifying respondents' above.

2. Key Worker Perspective

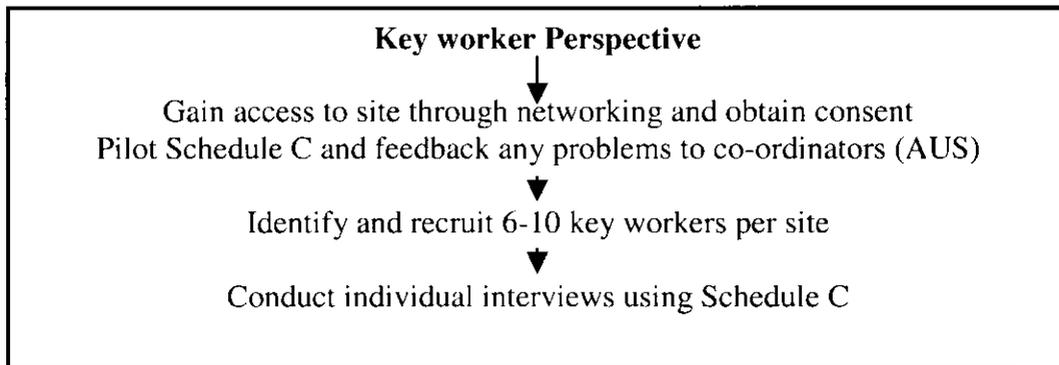


Figure 3: Data Collection flow chart for Key worker Perspective per Site

Criteria

For the purposes of this study, a 'key worker' (or 'internal/external actor') is defined as a worker who is paid (by an organisation/agency) to provide hands on care to the older person. A key worker may be either qualified or unqualified, but should be working directly with the client. Key workers who are working with user/carer respondents will be purposefully targeted, but where this is not feasible then recruited key workers should at the very least be working with the same (identified) client group.

The number recruited will vary between projects, but is anticipated to be between 6-10 people. Workers will be accessed in accordance with local organisational protocols and local ethical guidelines.

Individual semi-structured interviews will take place at a venue and time convenient to the participant, and as before, tape-recorded. The majority of the National Reports identify communication issues and organisational barriers between professions as an impediment to integrated care. The purpose of this data will be to explore the key workers' experience of the delivery of their client's care within an integrated care system, and to highlight any comparable mis-match of perceptions between clients and their professional carers (see Schedule C). In addition, the meaning of 'joint working' or 'seamless care' to the key worker will be explored, to establish how organisational pursuit of this concept might affect the staff involved in managing or providing care, and whether it corresponds to the value system of individual workers.

Summary of key worker data gathering process:

1. For each model, identify potential respondents and approach (according to local ethical guidelines):

6-10 key-workers
2. Conduct and tape-record semi structured interviews for each key worker.
3. Ensure respondents can be linked to data.

3. Organisational Perspective

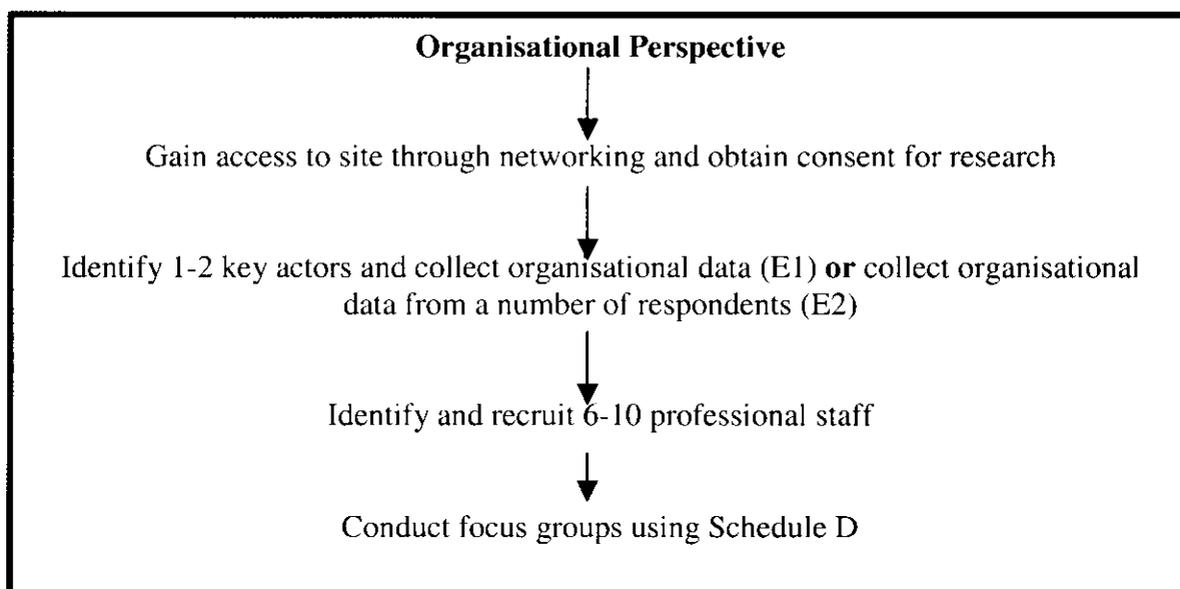


Figure 4. Flow chart of data gathering to establish organisational perspective

Organisational Database Information (Schedule E1 or E2)

The purpose of gathering this information will be to obtain baseline information about how the organisation currently operates. It will assist in identifying the extent to which factors such as the organisational infrastructure, human and financial resources support the delivery of integrated care and fit into the wider health and social care context of each country. The type of information collected will vary across countries according to its availability and accessibility, therefore it will be important to consider a site that will facilitate this process through routine data collection and/or auditing of performance. Networking within each site will be vital to identify relevant contacts that can assist with gathering this information.

Access and Organisational data

For the purposes of this study, the term 'organisation' is understood to mean the model that is being researched. Some models may consist of a group of organisations that are working together to provide an 'integrated care system'. There should be at least one interface between health care and social care systems, for example hospital/community care, community health care/community social care.

It is anticipated that access to the model project will be gained through one or more key actors within the organisation, and that 'organisation baseline data' will be collected either through interviews with key actors (1-2) within the organisation, or through discussions with a number of individuals. This data will focus on the 'structure' component of Donabedian's (1980) framework. Schedules E1 and E2 are proposed as a format to assist with organisational baseline data. Schedule E1 is an interview schedule designed for a key actor who would have an overall perspective of the organisation's development, strategy, financing and future planning. This may provide all the information required by Schedule E2. However, it may be that not all the information can be gained from one person, or that a number of individuals will be able to contribute to collection of baseline data, without necessarily taking part in a formal interview for the project. For this reason, Schedule E2 has been designed to act either as a 'checklist' or as a data-gathering tool. Individual teams can then decide how best to access this data in the models they are studying.

Focus Groups with Staff (see also p.4, methodology)

Criteria

A purposeful sample of staff working within the integrated care service will be identified. This will vary according to local structures, but may include managers, doctors, therapists, nurses, care managers, social workers and administrators. In some countries, it may be relevant to include the perspective of those who refer to the service who may be able to inform on issues such as access, responsiveness and communication, and those who commission the service, who would provide a view on cost-effectiveness. The size of the sample will vary according to the complexity of the service, but it is anticipated that a minimum of 6-10 people per site will be recruited.

This data will contribute to exploring both the 'structure' and 'process' elements of Donabedian's (1980) quality assessment framework. The purpose of conducting these focus groups is to discover staff's beliefs, attitudes and experience of integrated care, and to identify how the organisational process affects integrated working.

According to Gibbs (2003), focus groups normally consist of 6-10 people (although larger or smaller groups may be feasible) and last 1-2 hours. Depending upon numbers and professional variety, it may be beneficial to interview staff within their own professional groups, which may mean conducting several smaller focus groups. This may assist in revealing any contrasting views or underlying tensions within working relationships that may not otherwise come to light. A decision to mix professional groups may lead to more perspectives being revealed, although there is also a risk that some participants may be unwilling to voice conflicting views. Above all, participants should feel comfortable with each other (Gibbs 2003). Questions will focus around collaborative working and elicit issues in relation to the nature and purpose of the service; what it is trying to achieve and how they achieve it; strengths of the service; the nature of any problems and how they are overcome; and the extent to which the service is patient-centred (see schedule D).

Summary of 'Organisational' Data Gathering Process:

1. Identify 'Key Actors' (1-2) within organisation.
2. Gain access via key actor or referral to other 'gatekeepers', ensure organisation is willing to take part.
3. Conduct interview with key actor (Schedule E1) or complete Schedule E2 through discussion with various actors or use both until as much information as possible is gathered.
4. Identify 6-10 staff, and gain access via gatekeepers. Obtain consent from individuals, then:
 - Group into profession and/or hierarchical levels as appropriate, according to local (country) decision.
 - Conduct focus groups with approximately 6 staff and 2 researchers – one to facilitate the discussion and one to manage equipment and take field notes – using Schedule D.
 - Ensure a method for identifying respondents in focus groups and linking quotes/comments to data transcriptions is in place.

Data Analysis

This phase will be concerned with developing explanatory models in relation to integrated care for each case study. The case studies will generate a variety of data on different dimensions, and will be subject to systematic analysis, pattern-matching the themes identified in each data source. Pattern matching involves intense examination and triangulation of data sources or multiple observations for patterns within the data, allowing the data to provide and explain emerging theories (Yin 1994).

With reference to each data source, information collected will be analysed according to its methodological requirement.

- Qualitative data accrued from in-depth interviews and focus groups will be thematically represented from tape recordings. Following discussion of this issue at conference, the German team will develop data analysis tools for this project and these will be grounded in the concepts and issues revealed within the national reports, the theoretical paper and in the existing literature surrounding integrated care. The UK and German team will comment further on data analysis issues following their meeting in July 2003.
- Health data will be quantified and subject to descriptive statistics
- Data already collated and statistically analysed (as collected for the organisational analysis) will be critically reviewed for reliability and validity.
- Each country should have transcribed and analysed data from at 1-2 interviews per model prior to the next conference in Berlin, October 2003. This should allow discussion of emerging themes and issues arising from data analysis.

Pattern-matching across the data sources will allow explanatory models and themes to emerge for each case. The models will then be applied in a process of analytical generalisation to wider theories of health and social care. This will strengthen the explanations and provide vital information upon which to develop models of practice that may optimise outcomes for users and carers of integrated care services.

Other Methodological Issues

Ethical Considerations

The Declaration of Helsinki (2000) provides ethical guidelines for research involving human subjects; researchers in each partner country will need to be aware of their own ethical, legal and regulatory requirements when undertaking the investigation. There are a number of ethical issues associated with this plan of investigation, and it is perhaps worth highlighting some key areas that will need to be taken into consideration.

Foremost is that participation will be required from a vulnerable group (older people and carers) and particular care should be taken to protect individuals from harm. Of specific concern may be the issue of coercion, manifest as older people feeling obliged to take part, especially if they are in receipt of services. In the UK, recruitment via a known member of staff is usually indicated to avoid gaining consent under duress. Before obtaining consent, potential recruits should be informed about the study and what is required of them, and reassured that any care will not be affected if they choose not to take part. Reassurance should be given that all information will remain confidential. These principles also apply to recruitment processes for other individuals, such as staff.

Timescale

April –June 03	Obtain ethical approval, gain access to research sites and begin networking for key contacts; pilot instruments
June 03 – Oct 03	Begin and complete data collection on both sites; commence data analysis

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Client Interview Schedule A

10-15 users (and/or carers) should be recruited for each model studied. The sample will be selected purposefully, and should fulfil the following criteria:

- Users and carers who are currently in receipt of services (or who have received services within the last month)
- Users and carers who have received the service provided by the model for a minimum of a month
- Able to communicate and establish own point of view

Data should be gathered by individual semi-structured interviews, using either Schedule A (for service users) or Schedule B (for carers). The purpose of these questions is to discover the user's perspective of the model studied, and explore whether their experience suggests that health and social care has been provided in an integrated (seamless, co-ordinated) manner. Ideally, the older persons in receipt of the service will be the respondents, but where this is not possible (due to cognitive or sensory impairment) carers may be asked to respond on behalf of users. Carers and users should be interviewed away from each other where possible so that candid opinions can be gathered from each group of respondents. Questions in **bold print** should be asked during all interviews, and questions in italics are intended to guide further exploration of topics.

Suggested introduction to interview:

*We would like to find out something about your experiences of (*selected innovatory service). Thinking about your most recent experience of this service, we would like to take you through step-by-step and ask some questions about this.*

QA1. Services Received

What services do you receive from (model studied)?

*How long have you been receiving this service/these services for?
How often do you receive it/them? (e.g. how many times a week, or a day)*

Or, for day care or resident care:

*How long have you been attending (centre)
How often do you go to (day centre)
What sorts of services do you get at (day centre or residential centre)? (E.g. advice, personal care, physiotherapy, meals etc)*

QA2. Initial Contact

Describe how you contacted (or were put in touch with) this service.

*What were the events leading up to this?
Was it a self-referral, or did a professional or family caregiver make the referral?
Were you in hospital at the time or at home?*

*Who was the initial contact with?
How did you feel about the initial contact?*

What (if any) were your expectations of this service?

*Did you feel you needed this service?
Was it the right thing to do?*

QA3. Needs Assessment

**Did (the professional) ask you questions about your health and social care needs?
If so, can you describe this experience to me?**

*Were you aware of any assessment (of your needs) taking place?
If so, was there just one assessment, or more than one?
Were you provided with a written care plan? (or similar). If so, where was this document kept? Do you know why it was written?
Was there a waiting list to receive any part of the service?
Did you get the care you needed (from this service) when you needed it?*

QA4. Evidence of Person-centred Care

**Did you feel that you were involved in any decisions taken about your situation?
Could you have a say in what happened? (please give examples)**

*Did you get what you wanted?
Were your wishes respected?
Were your needs respected?
Did a relative (or spouse etc) arrange for you to receive this service? If so, did you feel confident that your relative knew/understood what you needed?
What sort of information was provided by the service? Was this the right sort of information for you? Was it presented in a way you could understand?*

QA5. Evidence of Joint working/seamless care

**Did the staff keep you informed about your *case? (or *request or *assessment or *enquiry)
If so, how did they keep you up to date with your progress?**

**How many different services do you receive?
How many staff members are involved with your care?**

if more than one, ask:

**Do different staff members know what they are each doing for you?
Are different staff members aware of how you manage?**

*Did you/do you know which worker is in charge of your case?
Who would you get in touch with if you had any questions or concerns about your *case?
If there are any changes in your condition, do you think that (they) would both be aware of this? If so, how?*

QA6a. Experience of Service

(based on responses to Q5 above, try to discover the clients' experience of *each* of the model's integrated services). Countries will need to formulate this question in relation to the service they are investigating

e.g. Could you describe your experience of receiving personal care from (service) carers?

OR Could you describe your experience of home adaptations by (service)

OR Could you describe your experience of day care by (service)

OR Could you describe your experience of being assessed by (service)

Would you say that the service has met your needs?

Could you describe how this service has changed things for you?

Could you arrange to attend clinics OR to have adaptations made at a time that suited you? (Or your relative/carer if they also needed to be present.)

QA6b. Experience of personal care (OPTIONAL - only use this question if personal care is part of the service provided)

What is your experience of personal care given to you by paid carers?

Was enough time allocated to you?

Could you request a care-giver with whom you felt at ease? (E.g. Male carer for male client)

Could you ask for carers to come at a time convenient to you?

Was the service reliable? i.e. did carers turn up when you expected them? Did you know which carer was coming, and why they were coming? Were you told about carer's holidays in advance, and was there cover available? What about if a carer was unwell?

If a new carer was coming, did they know about your needs/ how to care for you?

How did your carers manage sensitive issues such as dignity, privacy or confidentiality?

Could you talk about your worries or feelings with your carer?

QA7. Discharge issues

(OPTIONAL – use only if:

- **The model being investigated has a documented discharge process, and**
- **The client has some experience of being discharged by the service**

to discover how client is discharged from the service and what follow up measures and integrated communication measures exist. This does NOT relate to hospital discharges or previous discharges from other services, although the client may of course make comparisons)

Could you describe your experience of the discharge process from this service?

Did you have any problems when the service ended?

After the service ended, did anyone get in touch with you to find out how you are getting on?

Do you think you were discharged (from this service) at the right time?

What was the reason for discharging you from this service?

Would you say that the service had met your needs?

Did you feel that you were ready to be independent of the service?

What, if any, support did you have when the service ended? (This could be support from family or friends, or support from the service prior to discharge, e.g. information about discharge, other agencies that might help.)

If a new service started, did they know about your needs?

Were there any arrangements for getting in touch if you needed the service again?

What, if anything, could be done to improve discharge from this service?

QA8. Overall experience of this service

Could you describe your overall experience of (model)?

What, if anything, could be done to improve this service?

What was the best thing about this service?

What was the worst thing about this service?

Do you have any comments about the cost of this service? (Did you get any financial help? Was it enough to allow you to pay for the service?)

Carer Interview Schedule B

We would like to find out something about your experiences of (selected model) from your perspective as a carer. Thinking about your most recent experience of this service, we will take you through step-by-step and ask some questions about this.

QB1. Services Received

What services does your relative receive from (model studied)?

How long have they been receiving this service/these services for?

How often do they receive it/them? (e.g. how many times a week, or a day)

Or, for day care or resident care:

How long has your relative been attending (centre)

How often do they go to (day centre)?

What sorts of services do you get at (day centre or residential centre)? (E.g. advice, personal care, physiotherapy, meals etc)

QB2. Initial Contact

How did you/your relative come to be in contact with this service?

Why did you contact with this service?

What were the events leading up to this?

Were you providing care to your relative before the service became involved?

If so, could you describe what sort of care you were providing?

Are you still providing care to your relative?

Did you make the referral, or did a professional make the referral?

Was your relative in hospital at the time or at home?

Who was the initial contact with?

How did you feel about the initial contact?

What (if any) were your expectations of this service?

Did you feel you/your relative needed this service?

Was it the right thing to do?

QB3. Needs Assessment

Did (the professional) ask you questions about your relative's health and social care needs? If so, can you describe this experience to me?

Were you aware of any assessment (of your relatives needs) taking place?

If so, was there just one assessment, or more than one?

Were you (or your relative) provided with a written care plan? (or similar). If so, where was this document kept? Do you know why it was written?

Was there a waiting list to receive any part of the service?

Did you get the care you needed (from this service) when you needed it?

QB4. Evidence of Person-centred Care

Did you feel that you were involved in any decisions taken about your relative's situation? Could you have a say in what happened? (please give examples)

Did you get what you wanted?

Did your relative get what he/she wanted?

Were your wishes/needs respected?

Were your relative's wishes/needs respected?

Did you feel confident that you knew/understood what your relative needed?

Did you feel confident that the services staff knew what your relative needed?

What sort of information was provided by the service? Was this the right sort of information for you? Was it presented in a way you could understand?

QB5. Evidence of Joint working/seamless care

Did the staff keep you informed about your relative's case? (or request or assessment or enquiry)

If so, how did they keep you up to date with their progress?

How many different services does your relative receive?

How many staff members are involved with your relative's care?

If more than one, ask:

Do different staff members know what they are each doing for your relative?

Are different staff members aware of how much your relative can manage?

Did you/do you know which worker is in charge of your relative's case?

Who would you get in touch with if you had any questions or concerns about your relative's case?

If there are any changes in your relative's situation, do you think that (all the agencies involved) would be aware of this? If so, how?

QB6a Experience of Service

(based on responses to Q5 above, try to discover the carer's experience of each of the model's integrated services). Countries will need to formulate this question in relation to the model they are investigating. E.g:

Could you describe your relative's experience of receiving personal care from (service) carers?

OR Could you describe your relative's experience of home adaptations by (service)

OR Could you describe your relative's experience of day care by (service)

OR Could you describe your relative's experience of being assessed by (service)

OR Country variation

Would you say that the service has met your relative's needs?

Could you describe how this service has changed things for you/your relative?

Could you arrange for your relative to attend clinics OR to have adaptations made at a time that suited you?(if carer needed to be present.)

QB6b. Experience of personal care

(OPTIONAL - only use this question if personal care is part of the service provided)

What is your experience of personal care given to your relative by paid carers?

Was enough time allocated to your relative?

Could you request a care-giver with whom you and your relative felt at ease? (E.g. Male carer for male client)

Could you ask for carers to come at a time convenient to you?

Was the service reliable? i.e. did carers turn up when you expected them? Did you know which carer was coming, and why they were coming? Were you told about carer's holidays in advance, and was there cover available? What about if a carer was unwell?

If a new carer was coming, did they know about your relative's needs/ how to care for your relative?

How did your carers manage sensitive issues such as dignity, privacy or confidentiality?

Could you talk about your worries or feelings (about your relative) with your relative's carer?

QB7. Discharge issues

OPTIONAL – use only if:

- *The model being investigated has a documented discharge process, and*
- *The carer has some experience of their relative being discharged by the service*

to discover how client is discharged from the service and what follow up measures and integrated communication measures exist. This does NOT relate to hospital discharges or previous discharges from other services, although the carer may of course make comparisons)

Could you describe your relative's experience of the discharge process from this service?

Did you or your relative have any problems when the service ended?

After the service ended, did anyone get in touch with you to find out how you are managing?

Do you think your relative was discharged (from this service) at the right time?

What was the reason for discharging your relative from this service?

Would you say that the service had met your relative's needs?

Did you feel that your relative was ready to be independent of the service?

What, if any, support did you have when the service ended? (This could be support from family or friends, or support from the service prior to discharge, e.g. information about discharge, other agencies that might help.)

If a new service started, did they know about your relative's needs?

Were there any arrangements for getting in touch if you needed the service again?

What, if anything, could be done to improve this service?

QB8. Overall experience of this service

Could you describe your overall experience of (model)

Could you describe your relative's overall experience of (model)?

What, if anything, could be done to improve this service?

What was the best thing about this service?

What was the worst thing about this service?

Do you have any comments about the cost of this service?(Did you/your relative get any financial help? Was it enough to allow you to pay for the service?)

Key Worker Individual Interview Schedule C

- For use with 'key workers' linked to user/carer respondents
- Key workers should be delivering 'hands on' care to client **or** client group
- Purpose – to identify experience and role of key workers in a setting which provides integrated health and social care
- 6-10 interviews per selected site

Throughout this schedule, questions in '**bold**' print have been identified as essential and should be asked in all interviews, and in as much depth as possible. Questions in italics are optional and intended to be for guidance and to help explore topics.

QC1a. Key Worker's individual role

**I'd like to talk to you about the job that you do....
Could you describe a typical working day?**

**What sort of things do you do?
Do you enjoy your work?
What is good about your job? Can you give examples?
What is bad about your job? Can you give examples?**

QC1b. (Pay, hours, conditions, job security, job satisfaction)

**Do you enjoy your job?
Are you satisfied by your working conditions (hours worked, breaks, environment)?
Is your pay reasonable for the job that you do?
Do you get paid holidays?
Do you get increased pay for unsocial hours? (nights, weekends, evenings)
Do you feel that your job is secure?
Are you ever asked to do things that you don't feel trained (or ready) to do?**

(This may be a sensitive subject. In some cases it may not be possible to ask direct questions about salary and terms and conditions. The following questions are suggestions if a more general approach is needed)

*How are your hours (duties) organised?
Do you have any say in how your work is organised?
Do you feel secure in your job? Can you tell me why? (Or why not)
What are the working conditions like?(please provide examples)
Do you feel valued? (by your organisation, by your managers, by your team, by your clients)
Do you feel supported? (by your manager, by your team)
Do you think that you are paid well enough for the job that you do?
What opportunities are there for training/education?*

QC2. Integrated Care/Evidence of Joint Working/Seamless care

Does your job involve ‘integrated working’ (seamless care or coordinated care) between health and social care?

Could you tell me what ‘joint working’ (or seamless care or coordinated care) means to you?

Would you say that all the professionals/agencies involved in your client’s care are able to collaborate and work together for the client?

Do you know the other professionals/workers who are involved with your clients?

Are you able to contact these individuals if the need arises to discuss a case?

Can you plan any changes to care alongside other professionals?

To what extent are you able to work together with other health and social care professionals (or workers)?

How does ‘joint working’ affect your working practice on a day-to-day level?

*How do you communicate with other professionals/agencies involved in your client’s *case?*

Is a ‘lead professional’ identified? (i.e. between health and social care, not within a group of the same profession). Could you describe how the lead professional is chosen, and how this is communicated to the client?

What advantages/disadvantages exist for you as a member of a ‘joint working’ service?

Compare your role now with other jobs that haven’t been about joint working. What do you do differently now?

(this question is intended for employees of new ‘schemes’ which have been set up for joint working, and who have previously worked in different settings)

Does your organisation support you in ‘joint working’?

Have you experienced conflict with other professional groups? Are you able to give some examples of this?

Have you experienced collaboration with other professional groups? Are you able to give some examples of this?

If there has been conflict, does your organisation help you to find solutions to these problems?

Do you have time to co-ordinate meetings with other people who provide care/assistance to your clients? Are you able to share data about clients?

QC3. Access to service

Does your job involve helping clients obtain this service?

If so, please describe how clients access the service you provide....

Can individuals self-refer, or do they need to contact you through another professional, e.g. doctor or community nurse?

Do you think that potential clients are able to access this service if they need it?

Do you gather information about individuals who may contact your service but not receive the service for any reason? E.g. clients who decline to receive services, or who do not fit any criteria for suitability that may exist.

QC4. Needs Assessment

Does your job involve assessing whether or not a client needs a service?

If so, can you describe the process of assessing a client's needs within this service?

Is there usually one assessment, or do several professionals make their own assessments?

Who actually conducts the assessment?

How do you communicate the outcome of any assessment to clients/their carers?

Is there a written plan of care (or similar) for each client? If so, is this shared with other agencies involved? How is the plan of care reviewed/evaluated?

Is this service able to provide care/support/intervention to all clients that fit into the service criteria? I.e. are there times when assessed needs can't be met due to lack of resources?

Is there a waiting list for any part of this service? If so, how long would a client have to wait (on average) before receiving assessment/service?

QC5. Purchasing Care

Is your client charged for the service you provide?

If so, please describe how (this service) organises and supplies care or interventions or adaptations for clients...

In your view, is the service provided to your clients reliable?

Are your clients able to afford this service?

Could you describe how this service has changed things for your client or their family carers?

Is there a waiting list for any of the services you provide, including assessment?

Could your client (or their carer) arrange to attend clinics OR to have adaptations made at a time that suited them? (or you, if you needed to be present too).

QC6. Person-centred care (or 'holistic' care)

How do you see 'person centred' care?

How do you involve clients and/or their carers in decisions about their cases within this service?

Are you able to discuss each case with the clients involved? (assuming that the client is cognitively able to do this)

To what extent are family carers involved in decisions?

Does the client have a say in the outcome of their case?

Are there any arrangements in place to get 'feedback' from users about the service? If so, how is this information used within the organisation?

QC7. Discharge issues

(OPTIONAL – use only if:

- The model being investigated has a documented discharge process, and*
- The key worker is involved in client discharge from the service*

to discover how a client is discharged from the service and what follow up measures and integrated communication measures exist. This does NOT relate to hospital discharges or previous discharges from other services, although the key worker may of course make comparisons)

Does your job involve planning discharge from the service with your clients?

If so, could you describe how discharge is planned within this service?

How do you assess whether a client is ready for discharge? What are the discharge criteria?

Are all other health or social care professionals involved with the client informed of an impending discharge?

Is there any follow up of clients after the service has ended?

Can clients or their carers self refer if they require the service again?

QC8. Overall Experience of Service

Could you describe how you see this (model)?

What, if anything, could be done to improve this service?

Are you able to compare this service with other similar services you have been involved with?

What do you think is the best thing about your service?

What do you think is the worst thing about your service?

Organisation Focus Group Schedule 'D'

In total, 6-10 members of staff from each model should be included in focus groups. All levels of the organisations should be represented amongst the respondents (possibly in separate focus groups, see p.13), and it should be possible to link comments and responses to the individual's professional role.

In the following schedule, questions in **bold print** are considered key questions and should be asked in every interview or focus group. The questions in italics are suggestions to animate the discussions or aid exploration of topics.

Section 1 – Joint working/seamless care

(Purpose of questions: to discover the organisation's definition of integrated care, and how/whether the organisation's **structure** supports integrated working between health and social care)

QD1a. What is your understanding of 'joint working' [*seamless care/*coordinated care/*integrated working/*transmural care] between health and social care?

Which other professionals (or professional groups) do you regularly (at least weekly) have contact with?

(the term 'workers' or 'persons' may be more appropriate than 'professionals' where the integration is with unqualified workers from a different agency, BUT this question does not refer to unpaid family carers).

To what extent are you able to work together with other professionals/agencies/workers?

QD1b. How does 'joint working' affect your working practice on a day-to-day level?

*What arrangements exist to help your organisation/staff communicate with other professionals/agencies involved in your clients *case(s)*

QD1c. Compare your roles now with other jobs that haven't been about joint working. What do you do differently now?

Is there clarity about where professional roles begin and end?

How does this service fit in alongside other services for the same client group?

Are policies and protocols clear?(i.e. are these written down, easy to find, often used by workers?)

Section 2 – Process (How the service is provided)

(Purpose of section: to identify the **process** of co-ordinated and collaborative service provision, from the organisational perspective, along the continuum from needs assessment to user feedback)

QD2a. Describe how clients access the service you provide....

*Do you think that potential clients are able to access this service if they need it?
Can individuals self-refer, or do they need to contact you through another professional, e.g. doctor or community nurse?
Are clients assessed before entry to the service, to see whether they are suitable?
Can this service provide care/support/intervention to all clients that require it/fit the entry criteria?
Would you consider that this service is 'demand-led' i.e. services are supplied to all clients that meet criteria, or is it 'supply-led' i.e. services are in short supply, and perhaps targeted at the most at-risk or vulnerable clients?
Can the service help everyone who fits the criteria? Is there ever a shortfall between supply and demand?
Is there a waiting list for any part of the service?*

Do you gather information about individuals who may contact your service but not receive the service for any reason? E.g. clients who decline to receive services, or who do not fit any criteria for suitability that may exist.

QD2b. Could you explain how client's needs are identified within your service?

*Is a holistic assessment of need conducted? (i.e. 'single assessment')
Is there usually one assessment, or do several professionals make their own assessments?*

Which of the following areas would the assessment (s) cover?

- Physical health/well-being*
- Functional health/well-being (ability to do PADL's or IADL's)*
- Mental health (e.g. emotions, safety, support, isolation)*
- Cognitive health (e.g. independence, decision making, presence of cognitive impairment such as dementia or side effect from stroke (CVA)*
- Current family and formal support (include voluntary provision)*
- Housing issues (e.g. appropriate housing for dependency, availability of 'aids')*
- Financial issues (ability to pay/savings/insurance)*

Is a written care plan drawn up to document assessment, needs and care or interventions? If so, is this given to users? Is it accessible to other professionals who are involved with the client?

QD2c. Is it your experience that the (model you work for) can provide person centred care?

*How are clients and /or their carers involved in decisions about their individual cases within this service?
What steps are taken to involve clients and carers in the audit of this service? – are there client or user feedback groups within the service structure?
What do you think your clients get from your service? Are you able to give examples?*

QD2d. How is discharge from this service organised?

(OPTIONAL – use only if the model being investigated has a documented discharge process, to discover how a client is discharged from the service and what follow up measures and integrated communication measures exist. This does NOT relate to hospital discharges or previous discharges from other services, although the organisational staff may of course make comparisons)

How are other professionals involved in a client's care included in discharge planning?

What sorts of criteria exist for deciding to discharge a client?

How are clients and carers involved in the discharge planning process?

What sort of follow-up/aftercare arrangements exist?

How do clients access the service if their needs change again after discharge?

Section 3. Overall perspectives of integrated working within this model

(Purpose of question: to identify evidence of solutions to joint working problems within the organisation)

What could be done to improve this service?

What are the best examples of improved joint working that (this model) offers? (ask for details/examples)

What are the main continuing problems with joint working experienced by (this model) (ask for details/examples)

Is (this model) under any sort of threat? E.g. funding, competition

Is this model likely to be adopted, or to expand in your country/area?

What would you do differently after experiencing joint working or what might you do differently to promote joint working between health and social care?

Schedules E1 and E2– Baseline Organisational Data

This data may be collected through interviews with key individuals within the organisation (such as senior manager, service commissioner in local or regional government) or from administrators, or from a number of sources. The following schedules include study entry criteria, and baseline organisational data identified by the ‘organisation’ workgroup at the Canterbury conference. The Schedules are presented in two formats, Schedule E1 for a ‘key individual’ interview and Schedule E2 – a checklist for baseline organisational data.

Section 1. Service Purpose and Service Development

(Purpose of these questions: to ensure that the model studied fits the study criteria)

- As with other schedules, key questions to be asked at each site are in **bold print**, and exploratory questions are in italics

Please describe the service that this organisation provides to older people
(*e.g. home care, home adaptations, nursing care, personal care, carer support*)

How long has this service (model/organisation) been operating?
(minimum 6 months – study criteria)

How many staff are employed by the service? (minimum 15 – study criteria)

How many users/carers/clients does the service have? (minimum 15- study criteria)

How does this service integrate health and social care provision for older people?

In what ways is this service innovative, compared to existing services?

Q 1. Can you describe how this service developed?

- **Was it designed for a specific purpose/need?**
- **How was this need/purpose identified?**
- **Was it a response to an existing (government) policy? Or new legislation?**
If this is the case, please describe which policy/legislation led to this service being developed.
- **How does this service meet the aims of the policy/legislation?**
- **Was it a collaborative venture? If so, which agencies or organisations or government departments or professional groups were involved?**
- **How does this service manage the integration of health and social care?**
Ask for details, such as number of organisations, number of separate professions, other involved agencies (voluntary, lay, religious, political groups).
- **How is this service financed?** (*if this information is freely available, check whether it can be divulged if there are sensitive commercial interests*)
If there are a number of finance sources, ask about the percentages contributed from each source
- **Where does this service fit into the existing framework of service provision?** *Is it a project or a mainstream service? Will it exist in the*

medium/long term, or is it a pilot service? Does it replace or compete with existing services?

- **Which of the following does the service have:**
 - Written quality management policies (e.g. procedures and protocols)
 - Policies/protocols for managing collaboration between health and social care organisations (or their professional representatives) – *for example managing shared records, deciding which is the 'lead' professional, identifying who is accountable for the clients' care*
 - Statistics about service uptake (*are these published?*)
 - Statistics about services allocated to clients
 - Statistics about clients excluded from services/referred to other agencies
 - A written complaints procedure for users
 - A format for regular user/carer feedback (*i.e. not just feedback arising from complaints*)
 - A written flow chart/care pathway
 - Written care plan (*where is this kept? Is it paper or computer based? Does the user/carer have access to it or input into it?*)
- **How is the service being evaluated?** (*is there ongoing research? Is this conducted by external bodies, or is it conducted by the organisation? Is it evaluation conducted by audit, or more in-depth methods?*)

Schedule E2

(Minimum baseline organisational data checklist)

The following table lists the minimum data items to be addressed within organisations. Its purpose is to offer a checklist for baseline organisational data, and an accessible format for displaying model project data from the participating countries.

<i>Date</i>	
<i>Researcher name</i>	
<i>Researcher centre</i>	
	<u>1. Study entry criteria:</u>
Name of Model:	
Contact Person (s):	
Contact details: Phone no, email etc	
Source(s) of Data:	
Date model commenced providing service:	
Number of staff employed by service:	
Number of users/carers/clients:	
How health and social care are integrated by this model:	
Describe how service is innovative, compared to (pre) - existing services:	

	2. Organisational Data
Organisations involved:	
Professions involved (include numbers for each)	
Goals of Model:	
Service(s) Provided:	
Annual Budget (EUR)	
Sources of funding: (show % if known)	
Length of time funding secured over:	
Methods of audit/evaluation:	
Methods of user/carer feedback:	
Complaints procedure available?	
Written organisational policies available?	
Written care plans for users?	
Written care pathway available to clients?	
Discharge procedure available (to staff/users)?	

Schedule F –Health Profile data

1.Date: _____

2.Name (or linked anonymous code) of respondent: _____

3.Respondent is a:

- Service User
- Informal (family) carer for a service user
- Formal carer (e.g. care manager, nurse, therapist, home carer)

(tick as appropriate)

4.Health Profile data (must relate to service user not carer!!)

4a. Age: _____

4b. Gender: M/F

4c. **Main health and social problems (user perspective ideally, carer perspective if service used is unable to take part):**

5. Level of ‘Formal Care’

(Definition of ‘Formal care’: Care which is provided by any agency or organisation outside the service user’s immediate family, usually following an objective or professional assessment of the client’s needs. Care is usually purchased by the client or on behalf of the client, although it may be provided through a voluntary agency.)

(Tick as appropriate)

- Client receiving 24 hour medical care in hospital/acute unit
- Client receiving 24 hour nursing care (but not medical care) in nursing ward or nursing home
- Client receiving 24 hour social care in residential home/unit

(Continued overleaf)

Client receives the following formal care in own home (complete for a typical week):

	<u>Personal Care*</u>	<i>(no of visits)</i>	<u>Social Care*</u>	<i>(no of visits)</i>	<u>Social Support*</u>	<u>Other</u>	<u>Notes</u>
Example	Yes	3	Yes	1	30 min - chat	GP visit	fall
Mon							
Tue							
Wed							
Thursday							
Friday							
Saturday							
Sunday							

Other types of formal care received at (or from) home over a typical week*:

	<u>Nursing Care*</u>	<u>Therapy* (specify)</u>	<u>Therapy (specify)</u>	<u>Hospital Outpatient*</u>	<u>Day-care*</u>	<u>Notes</u>
Mon						
Tue						
Wed						
Thursday						
Friday						
Saturday						
Sunday						

OR

Client receives no formal care

6. Level of Informal Care

Definition: 'Informal Care' is care provided by spouse, family, friends or neighbours on a voluntary, unpaid basis.

It can be really difficult for carers to know how much time they spend giving personal care, social care (help with shopping, cooking etc) and social support. One simple approach is to gather the following data:

How many informal carers provide care to this person?

What sort of care do they provide?

How much time in total (estimate) do they spend giving this care?

E.g. For a man whose wife tends to him 24 hours a day, 7 days a week (i.e. he would need 24 hour care if his wife was not there), and whose son does shopping and pays bills for his parents, and also visits on Sundays:

2 informal carers (wife and son)

Personal care, IADL care and social support provided by wife 24/7 (148 hrs per week)

IADL care and social support provided by son (8 hours per week)

= 168 hours per week informal care

Alternatively, a chart could be completed, e.g.

Informal Care Dependency:

Client receives the following informal care:

	Personal Care (hours per week)	Social Care (hours per week)	Social Support (hours per week)	TOTAL
Main Informal Carer e.g. wife				168 (with client 24/7)
Informal Carer 0 2 e.g. son	0	2 (does shopping/finances)	6 (spends Sundays with parents)	8
Informal Carer 3	N/A			
Total				176

OR

Client receives no informal care

Glossary

Day care: Transported to a day centre, provided with (for example) social support, meals, hobbies, entertainment, advice, possible access to other services such as hairdressing, chiropody, therapies.

'Hospital Outpatient' Attending clinic at a hospital (or other acute/sub acute provider) for consultation/appointment with specialist medic, nurse or therapist. Individual appointment, not 'day-care'.

'IADL' 'Instrumental Activities of Daily Living', for example cooking, cleaning, shopping, housework, budgeting, etc but not 'personal care' (see PADL)

'Key worker' (or 'internal/external actor) is defined as a worker who is paid (by an organisation/agency) to provide hands on care to the older person. A key worker may be either qualified or unqualified, but should be working directly with the client.

'Nursing Care': Care provided by a qualified nurse (or delegated by a qualified nurse to a nursing assistant), such as wound dressings, drug administration, nursing assessment.

Organisation For the purposes of this study, the term 'organisation' is understood to mean the model that is being researched. Some models may consist of a group of organisations that are working together to provide an 'integrated care system'. There should be at least one interface between health care and social care systems, for example hospital/community care, community health care/community social care.

'Other' forms of service provision could include using a call out service after a fall, visiting pharmacy, visiting sitting service – i.e. individuals who sit with client to give spouse or other family carer a break. Please alter anything relevant to your country/model

'PADL' 'Personal Activities of Daily Living' such as washing, dressing, grooming, feeding, toileting, bathing, showering, mobility

Personal Care : Assistance with 'PADLs' (personal activities of daily living).

Social Care: Assistance with 'IADLs' (Instrumental activities of daily living) such as cooking, cleaning, shopping, gardening, laundry, arranging personal finances

Social Support: Visits from friends/family/formal carers for social or emotional support rather than to attend to tasks, for example taking person out for walks or meals or for visits to other family members, taking person on holiday, reducing isolation, increasing quality of life, maintaining relationships

'Therapy': May include Occupational Therapy, Physiotherapy, Rehabilitation or 'health maintenance' therapy, exercise therapy, speech therapy, dietician. Please enter data relevant to your country/model.

'Typical week': the data should reflect 'usual' service use, but as people may be accessing the models under discussion at times of increased need or even crisis, this may be difficult to estimate. Where possible use the previous week, unless this is

really atypical (e.g. client was in hospital or short term residential care or on holiday with family etc).