

Research Across the Social and Primary Health Care Interface: Methodological Issues and Problems

Enid Levin, Research Unit, National Institute for Social Work, London

Barbara Davey, Nursing Research Unit, King's College, London University

Steve Iliffe, Department of Primary Care and Population Sciences, Royal Free and University College Medical School, UCL, London

Kalpa Kharicha, Department of Primary Care and Population Sciences, Royal Free and University College Medical School, UCL, London

Abstract

The policy of much closer working between health and social services increases the importance of developing robust methodologies to evaluate the processes of collaboration and their outcomes for service users and carers. The policy assumption that closer integration should yield more positive outcomes remains largely untested in systematic studies with a comparative design. This paper describes a feasibility study for such a comparison, and outlines the problems encountered. These include variable involvement of social workers, difficulties in engaging general practitioners, inconsistent documentation of social care in general practice records, and ethical difficulties in engaging older people in service evaluation.

Introduction

Since 1997, a raft of legislation, guidance, and funding for special initiatives has moved joint working up the agenda. Health and social services are now exercising a new duty of partnership, working together on the boards of Primary Care Trusts (PCTs), and availing themselves of the new flexibilities for pooled budgets, lead commissioning and integrated provision under *The Health Act 1999*. Most recently, the *National Service Framework for Older People* has promoted a single assessment process that will span general practice, community nursing, social care and specialist medical services as well as integrated commissioning arrangements and integrated provision of services (Department of Health, 2001).

Working in partnership is not an end in itself; rather, it is intended as a means to the end of better outcomes for service users and their carers. The policy assumption that closer integration should yield more positive outcomes derives from observational studies (Ross and Tissier, 1997; Cooke et al, 2001) and with some exceptions (Rummery, 1999) remains largely untested in systematic studies with a comparative design. Although it is reasonable to expect that some arrangements for collaboration between social and primary health care practitioners are more effective and efficient than others, there is insufficient research evidence to verify or falsify this hypothesis.

A literature review (Kharicha and Webb, 2001) confirms that a stream of studies over thirty years have examined the factors sustaining and frustrating collaboration, and have assessed small

pilot schemes designed to improve co-operation. Many schemes involved the attachment of named social workers to one or two self-selected general practices in which the doctors were committed to partnership, and the evaluators focused mainly on the benefits of collaboration from a primary care perspective. Typically, such studies found that attachment was popular with these GPs, and increased trust and the understanding of each others' roles among involved and motivated professionals. They raised concerns as to whether the schemes targeted the same groups of clients as mainstream social services. Of the smaller number of studies comparing GP attachment with standard approaches, most have focused on processes, contacts, and GPs' and social workers' perceptions of each other, rather than on their outcomes for service users and carers; conclusions broadly similar to those reached in an independent review (Lymbery, 1998).

The form of arrangements for inter-agency and inter-professional working is not nationally prescribed. In most areas, social services and primary health care practitioners have worked on separate sites and in separate teams with loose, informal links for cross-referring and exchanging information on individuals. An inspection by the Social Services Inspectorate of eight social services departments identified a range of small-scale partnerships with effective integrated approaches in each area but found that '*social services and primary health services mostly worked in parallel lines, often leading to poor communication, duplication of efforts and frustration and delay for service users.*' (CI(99)22; O'Hagan, 1999: para. 1.8). This inspection and the work of the Health and Social Care Joint Unit found representatives of

social services departments on each Primary Care Group (PCG) board and identified PCGs/Trusts as one of the levers to shift partnership working from the margin to the mainstream of practice (Department of Health, 1999).

As more and more social services departments align their front-line workers closer to primary health care, a range of approaches to collaboration have emerged. These include:

- social services teams located in health centres
- social work attachment to general practice
- nominated link workers for GPs
- PCG/Ts and community nursing teams
- regular formal meetings between social workers, nurses and their managers
- social workers with their aligned nurses attending general practice meetings
- district nurse care managers in social services teams
- joint primary health and social care teams

In several respects, policy and practice are ahead of research in this area. Some but not all new arrangements are subject to independent or in-house evaluation using various methods and not always a comparative design. Once these arrangements bed down, large-scale studies across authorities will be required to compare the full range of approaches to partnership and to test the hypothesis that some arrangements yield better outcomes for service users and their carers than others.

Research across the service interfaces is complex and labour-intensive, requiring the co-operation of several disciplines and the use of a battery of methods and instruments. Therefore, a multidisciplinary team from the National Institute for Social Work and the Department of Primary Care and Population Sciences at the Royal Free and University College Medical School undertook a detailed study of the feasibility of comparing different mainstream arrangements for collaboration and of establishing their outcomes for service users, and to make recommendations on the design, methods and requirements for large-scale studies (Levin et al, 2001; McCrone et al, 2001). The study was funded for two years through the Outcomes of Social Care for Adults Initiative (OSCA) (Henwood and Waddington, 2002).

This paper focuses on the technical and methodological issues raised by our feasibility study and assesses their implications for further work.

The Aims of the Project

The prospective study assessed the feasibility of comparing two different approaches to collaboration between social services and primary care and of establishing their costs and their outcomes for people aged 75 and over and their carers.

The specific aims of the feasibility study were as follows:

1. to compare the characteristics, experiences and outcomes for older people assessed by two social services departments;
2. to track in detail the contribution of both health and social services to the care of people aged 75 and over referred to social services for complex assessment of need;
3. to identify the factors that promote or hinder working together;
4. to carry out an economic evaluation of the two approaches to partnership.

In meeting the above aims and complying with requirements of the Ethics Committee a wide range of instruments and documentation were used and developed. Quantitative research methods were used to test the study hypothesis that closer working between social services and primary health care results in better outcomes for older people. Both validated and standardised measurement instruments were used along with those tailor made to address the study aims. Qualitative methods were employed to explore practitioners' and team managers' views and experiences of joint working. See Appendix 1 for details of the full range of instruments used in the study.

The project has three special features. Firstly, we sought to compare the **mainstream arrangements for collaboration** in two social services departments and include a sample of community teams for older people and the general practices that they covered in order to assess fully the complexity, and the technical and resource

implications for large scale studies. Secondly, we created a **joint research team** with one project director and the health services researcher based at the Royal Free Hospital and the other director and the social services researcher based at NISW over two miles away. Our intention was that the research team would mirror the working conditions of many of the professionals in the project by working in separate organisations and on different sites. Therefore, we would use the same range of methods for communicating with each other and experience similar challenges in cross-agency transactions, including the time that they consume. Thirdly, for each older person recruited to the study and, with their consent or the agreement of their carer, we attempted to **log the service interventions and the contacts between practitioners** from referral to follow up interview, using paper and electronic templates with both the social workers and the general practices.

Location of the Study

The project was carried out with the co-operation of social and health care staff and service users and their carers in two London boroughs covered by one Health Authority, one NHS Community Health Services Trust and 225 GPs in 99 surgeries. We will describe these boroughs as Area One and Area Two.

The criteria for the selection of the areas were as follows: firstly, they should enable contrasts to be made between the arrangements for collaboration; secondly, they should be areas with high levels of morbidity and deprivation and hence a challenging environment for partnership working; thirdly, the costs of the study should be contained if possible by the areas' proximity to the research bases; and finally, there should be agreement in principle on the part of social services departments to co-operate in service evaluation.

Area One had pioneered the move of its social work teams for older people and adults with physical disabilities into health centres with some of the community nurses. At the start of the project, there were five teams for long-term care management of complex cases located in health centres across the borough plus a central assessment team, two multidisciplinary teams for older people with mental health problems and

social work teams in hospitals. Sources of variety in the health centre teams included whether there were any GPs in the buildings and the continuance of a social work attachment scheme to co-located group practices in one health centre.

Area Two initially had five teams in local authority community care centres plus social workers and multidisciplinary teams in hospital. The community care teams were not co-located with community nurses or GPs but each team included a district nurse care manager for the assessment of very complex health needs.

The changes in organisational arrangements that occurred in both boroughs during our project are discussed later in this paper.

Methods of the Project

The nature of the evidence needed to assess the effectiveness of joint working between health and social care is determined by the diversity of perspectives on and conceptual facets of collaboration, the difficulties of measurement, and the choices to be made between macro- or micro-level evaluation, short and long term effects, and individual or social impacts (El Ansari et al, 2001). We opted for a mixed methodology design to capture professional perspectives, patient/client experiences and health status, carer perceptions and service utilisation (with a view to economic analysis). The methods that we used included:

1. Interviews with a total of 69 managers and practitioners in social services and general practice to identify the strengths and weaknesses of current arrangements and elicit their views on the components of good practice in joint working and the training and support required to develop it.
2. Systematic collection of data on 224 people aged 75 and over consecutively referred to the locality teams and undergoing assessments of their needs after the start of the study. Those whose assessment resulted in immediate entry to residential or nursing home care were excluded from the study. The social workers were asked to invite those remaining at home to participate in the interview survey.

3. Baseline assessments of 79 older people (40 in Area One and 39 in Area Two) and interviews with 47 main carers to establish their social circumstances, mental and physical health and their perceived needs and preferences as soon as possible after referral and assessment. The interview schedules included closed and open-ended questions and standardised measures for the assessment of mental and physical state and satisfaction with services.
4. Follow-up interviews with the older people and the carers after six months, repeating some measures and eliciting their experiences of services and their evaluation of outcomes.
5. The refinement and application of methods to log and assess both the health and social care inputs into the care packages, including the amount, type and quality of communication from referral to follow up between social workers, GPs, and community nurses and with the older people and their carers, subject to the permission of the study participants.

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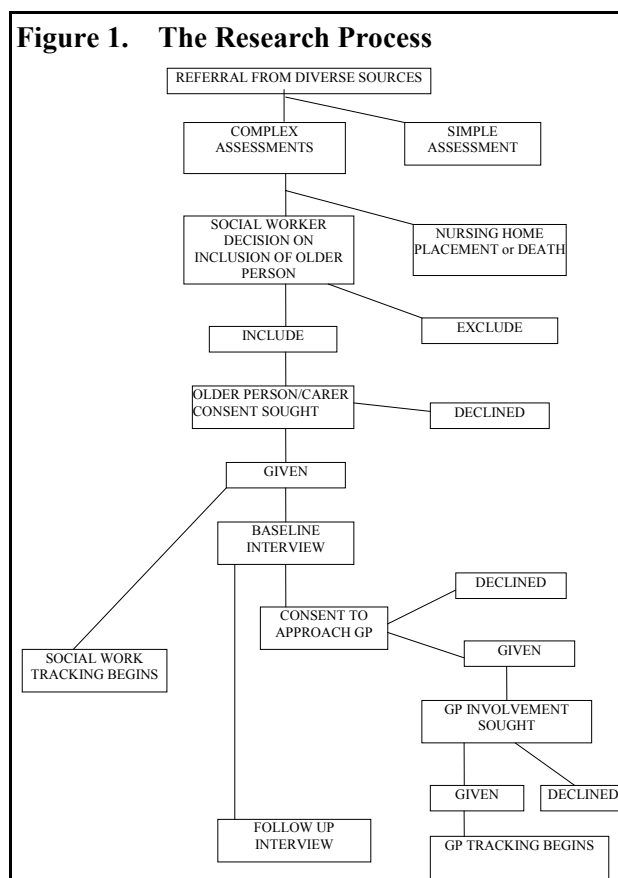
The research process is shown in Figure 1.

We shall now discuss the factors that promoted or hindered the achievement of the various aims and phases of the project.

Factors Affecting Research Across the Social and Primary Health Care Interface

This feasibility study was prospective in design as we wanted to interview the older people and, if they had them, their carers as soon as possible after their assessment by social services, and log communication between social services and primary care and the contribution of both organisations to their care packages from the point of referral to follow-up interview, entry into long-term care or death. This activity proved far from straightforward, for many reasons including the competing demands of services, participants and methodology as outlined by Ghate (2001). We have identified a wide range of factors which facilitate and mitigate against the successful achievement of such work which we shall discuss in detail. These factors are interlocked but may be divided up broadly into those external and those internal to the research process.

Figure 1. The Research Process



External factors include securing cooperation with social services and general practice and ethical considerations. The internal factors include the research team itself, the characteristics of the older people and the carers in the sample, the data collection process and instruments, and the sources of information and its quality.

External Factors

Securing and sustaining the co-operation of the partners for the research

The comments in this section should be interpreted in the context of the very high value that the research team places on the co-operation of the two social services departments, their community teams, and the general practices included in the study.

Social services

Social services departments are hierarchical organisations that work under pressure and are subject to resource and time constraints. Their senior managers have to take account of this reality

when approached to become involved in research, even when they have a strong commitment to rigorous service evaluation. Securing co-operation with external researchers, obtaining access to front-line teams, engaging the team members in long-term research and, through them, reaching their clients involves a lot of negotiation. In this project, this process involved the provision of documentation and then discussions with the two Assistant Directors and also with the middle managers for the social work teams, presentations to the team managers' groups, and then meetings with eleven teams of social workers to enlist their ongoing co-operation without which the project could not succeed.

Strong support for the project was forthcoming from both senior management teams, and most team managers and social workers were keen, co-operative and became actively engaged, confirming the argument that an empirical approach to the evaluation of practice is a core concern of social work (Gibbons, 2001). Their tasks were to be interviewed about arrangements for collaboration, to supply detailed prospective information on consecutively assessed people aged 75 and over, to approach service users eligible for the study, and to update the researchers either face-to-face or over the telephone on service packages and contacts with primary health care at routine intervals between initial and follow up interviews. Therefore, building and maintaining a relationship with the social workers for several months was an essential part of the researchers' role.

In practice, the fulfilment of this remit proved much slower and more time-consuming than estimated by both the managers of the social services departments and by the research team on the basis of initially available information, a result with implications for the methodology and time-scale of future interface research requiring a representative sample of service users.

The first reason was that managers could strongly encourage social workers to assist the research team but could not in the last analysis insist that they took on additional tasks. These tasks were secondary to their main responsibility of meeting agency function by ensuring that very vulnerable

older people were safely supported at home using limited resources, pressures of work and in light of some professional autonomy and control.

Secondly, the motivation, willingness and ability of the social workers to participate was variable and seemed to be influenced by their work priorities, their commitment to the oldest group of service users when holding mixed caseloads, their own and the team morale, their interest in research, their views on its efficacy and, possibly, whether or not they liked the researchers and wanted to help them over several months and in changing circumstances. Social work research is constantly diversifying, expanding and changing, with conflicts between different ways of knowing, doing and valuing it (Gibbs, 2001), and social workers may judge research activity from the client's perspective, in terms of its practicality, capacity to empower and action orientation (Duckett and Pratt, 2001). The researchers had to negotiate working relationships with social workers, and in doing so had to accept that there are alternative ways of understanding the complex phenomena of practice in heterogeneous environments (Martinez-Brawley, 2001).

Thirdly, access to the referrals and assessments through the central computerised record systems was available but no more than a partial solution to the problem of securing new cases. There was sometimes a mismatch between the information held there and that in the teams due to time-lags, sudden changes and informal referral practices in the case of long-term teams. Lists of service users supplied by the centre did not always record the names of the allocated social workers or subsequent changes. These failings of data capture or transfer are significant given the overlaps in populations using different health and social care agencies (Keene et al, 2001).

Fourthly, the social workers and team managers could influence the pace of the research, especially when additional demands were placed on their time, for example, by staffing problems or an internal review. They were often out of the office or in meetings and hence not easy to contact by telephone. These difficulties are illustrated by the researchers' fieldwork notes:

Seen to interview. (Social worker) is very pressured over the next two weeks and works part-time. Agreed to contact her after three weeks to get the details of her cases and check if she has any new assessments.

Mrs X is being asked (to take part in the survey). Social worker has two other new assessments but still needs to do the first visit. Agreed to contact her in two weeks to check (if Mrs X has agreed) and complete forms on new assessments.

Finally, in the course of the project, social services in the two boroughs were delivered in the context of some perturbation in the working environment due to internal re-organisation, external and internal audit, team re-locations and mergers, and significant changes in policy and staffing, all of which had to be accommodated by the external research team. The perceptions that care managers were trying to reconcile increasing amounts of time spent on documentation with less time for making working relationships with clients and other professionals, and that as their tasks increase in complexity their work process become increasingly reductionist (Postle, 2002), resonate with the experience of the research team.

For example, Area Two reduced the number of community care teams from six to five which affected staff morale, workloads and willingness to participate in the research. The adverse impact of change on morale is consistent with the finding of higher-than-average stress levels (and low job satisfaction) in social workers in five other areas (Balloch et al, 1998). Another change was the introduction of a designated worker for older people with mental health problems into each team, having previously provided this service through a multi-disciplinary hospital team.

The other area, Area One, completed the move of all its community-based social workers into health centres and moved in stages towards nominated social workers linked to community nurses and their GPs. Some but not all the community nurses were co-located, only some had GPs on site, and two group practices retained attached social workers. This meant that variety was produced within the dominant model of social work in health

centres that we sought to compare with the looser, more traditional arrangement in the other borough.

As social services and primary care are reshaped to increase integration, it seems likely that change will remain the normal state in these services for the foreseeable future. Whilst stability on the front-line is desirable for practice and research, change may have to be accepted as the given context of research in this area and pragmatic approaches will be required to allow for comparisons and hold the research conditions as constant as possible.

These factors made it difficult to obtain a representative sample of service users and to minimise any bias in the sample from such sources as variable social worker participation. Other researchers have reported this problem, including our colleagues in previous studies (Moriarty, 1999; Moriarty and Webb, 2000), and other OSCA teams and academics now researching the social and health care interfaces (Henwood and Waddington, 2002). It is common in prospective studies that seek to sample older people as near as possible to the point of assessment. One alternative approach that we considered was a survey of all services users aged 75 and over on the workloads of social workers on a specified date. On the basis of our previous experience, this provides a study population quickly but has its disadvantages. First, it does not overcome the problem of variability in social worker participation. Secondly, the time between initial assessment and the survey for people on long-term care management caseloads varies from several years to less than a month, rendering it difficult to get accurate information on communications between social and health care staff, to ensure comparability between the groups of older people in the study, assess outcomes, and thereby achieve the study aims.

Every method has its advantages and disadvantages which should be made explicit. In our case, we took steps to compare the characteristics of the older people and carers in the sample with those of other samples of service users and with the information collected in the two boroughs on this client group. Initial work suggests that our sample is very similar to samples of older users obtained by various means (Moriarty and Webb, 2000).

Also, we can use the data on those included in the sample:

1. to explore associations between characteristics on initial interview, services received and outcomes,
2. to examine changes over time on several measures,
3. to describe their views of the services,
4. and to document and compare contact between social workers and primary care for each older person.

General practice

Whilst we have drawn attention to the variability in social workers' willingness and availability to commit to the project, we had the backing of the senior managers and the team managers as levers to involvement. Social workers in all the teams gave details of their new assessments, approached service users for us and set aside time to update us on their care management work with the sample over a six month period.

This context throws into sharp relief the differences between social work teams and general practice when forming partnerships for research. First, there is more professional and managerial autonomy in general practice than in social work and comparable managerial levers to obtain participation do not exist for general practice. Doctors can refuse access outright and even within willing group practices some GPs will commit themselves to the project and others will not. GPs, like social workers, vary in their interest and degree of expertise in the health problems of older people, their attitude to research, their availability, the size of their practice and the number of their support staff, and the pressures under which they work, especially in areas where deprivation and affluence co-exist. Above all, some doctors and practice managers have far more knowledge and experience of social services than others, and place a higher value on closer working and the potential contribution of social care services to patient well-being.

Each of the 99 practices encompassing 225 GPs was sent an information leaflet and letter by the project director in the Department of Primary Care advising them of the study and that we might

contact them as we could not ascertain beforehand how many GPs would be involved in the social services sample across both boroughs. We were asking for less time and involvement than from social services but some declined immediately or when we approached them because of prior research commitments or other reasons, and one requested payment. Those who participated with or without persuasion did so because of their interest in the research topic, their links with the University Department of Primary Care and the Medical School or their active membership of the new PCGs. Thus there was an element of self-selection among those approached for the tracking exercise because they had patients in the sample. Although the degree of co-operation varied, the response of this group was encouraging and with persistence we were able set up and try out tracking instruments to match those in social services for most of the sample, spanning group and single-handed practices with a range of paper and electronic record systems.

The impact of ethical requirements

The tightening of codes of conduct of the Local Research Ethics Committees' conditions for granting permission for research and the Data Protection Acts, in response to public demand, are positive recent developments. It must be recognized that meeting these stringent requirements has a substantial influence on the time-scales and the pace of progress in studies of service users.

Firstly, for sound ethical and legal reasons, social services departments will not provide external researchers with the names or addresses of those eligible for a project before they have approached them individually and been granted permission to do so. The researchers in our project, as in others, were dependent on the willingness and availability of practitioners to explain the project, provide the requisite information leaflet and enlist the co-operation of the older people and their carers. Telephone calls rarely sufficed as many service users eligible for the study had physical, sensory or cognitive impairments and, therefore, an extra visit was necessary or the request delayed until the next planned visit. Refusals occurred at this point which the researchers could only record.

A few refusals occurred once the older people were contacted because they had changed their minds, had found the assessment process they had just undergone trying or become ill. Again, the information leaflet required by the ethics committee clearly stated their right to refuse and also to terminate the interview at any stage, as happened in one case.

The social workers supplied information on 224 consecutive assessments of people aged 75 and over. Of these, 34 per cent (n=77) were included in the assessment analysis but not eligible for the interview survey because they went straight into long term care or, in a few cases, died soon after assessment. Of the 147 persons eligible, 18 per cent (n=26) were excluded by the social workers because of health or family complications, 28 per cent (n=42) refused, and 54 per cent (n=79) were interviewed. Thus the refusal rate for those invited to participate (n=121) was 35 per cent, a result which is similar to comparable research in the south-west of England (Brown et al, 2002).

For sound ethical reasons, there is little scope to lower the refusal rate among the older people. However, it may be possible to reduce the number of cases in which the practitioners decide that potentially eligible service users should not be invited to participate for reasons that were sometimes questionable.

The right and proper prohibition of direct access to service users without their prior permission was one of the reasons why recruitment into our sample was slow and a major source of frustration in the project. It took at best two weeks and at worst several months. One consequence was that we had to reduce the numbers for inclusion in the feasibility study sample from the target of at least 50 to 40 in each borough. In contrast, the follow up interviews were much easier to arrange as we had permission from the older people and the carers at Time One to contact them again directly. We were able to re-interview 74% (n=50) of the surviving older people either at home or in residential care.

Internal Factors

The research process is affected not only by the external environment in which it takes place but

also by other considerations that we have categorized as internal factors. These include the stability of the research team, the characteristics of the sample, the data collection methods used, problems in their administration, and the quality, reliability and interpretation of data yielded from many sources.

The research team

Stability in research teams is desirable for time-limited partnership research. The progress of this project has been influenced by intercurrent events that could not have been anticipated but which necessitated re-scheduling and re-allocating the work, changing the division of labour, and employing temporary staff and sessional interviewers. In the first year of the study we also had to contend with some mismatch in technology between the two sites, making it necessary to communicate mainly by telephone and fax rather than by electronic mail. In the second year, the work on the costs of care had to be re-commissioned due to the sudden departure of the first economist and subsequent changes in his unit. The researcher at the Department of Primary Care has remained with the project throughout and maintained continuity in the complex process.

The nature of the sample

The older people in the sample had been referred to social services because of their complex health and social care needs and requirement for long term support at home. A special challenge faced by the study stemmed from the proportion of older people in the sample who showed signs of moderate or severe cognitive impairment, as measured by the Mini Mental State Examination (MMSE) at initial interview (Folstein et al, 1975). The size of this sub-group was difficult to estimate in advance on the basis of the information from social services, confirming the finding that assessment approaches for older people receiving social care were variable and superficial (Stewart et al, 1999), but data analysis showed that about two-thirds of the sample were cognitively impaired. Two-fifths had marked or severe cognitive impairment and this group was unable to complete a full interview in the same way as those who were not cognitively impaired, although some were able to comment on services. Data on the service packages for the total

sample has had to be collated not only from the interviews with the older person but also from the interviews with the carer, if there was one, or from the social worker. This leads to problems of reliability and consistency. Also, it has implications for future studies in terms of the number of persons to be included in the samples, given that older people with dementia use more services than others and should not be excluded.

The tracking exercise

Two sets of instruments were developed for tracking the inputs of social and health care and the contacts between social workers and primary care for the older persons to follow up interview or death, one for use in social services and one for general practice.

The tracking forms for social services proved relatively easy to complete in face-to-face or telephone contact with the social workers who used their detailed case records and diaries for this purpose. Whilst information for management purposes is recorded electronically, most of the detailed information that we required is held in paper records. The only difficulties that we encountered were related to social worker accessibility, case transfers or closure and staff changes. Interpreting the data on contacts raises some interesting dilemmas. For example, we can count the number of contacts with the service users and between professionals but the stated reasons for them show that some are organisation-led rather than triggered by the needs of the older person. Thus re-assessments may occur because care packages are under review due to budget cuts or a difference of opinion about the respective contributions of health and social services.

The challenge of setting up and operating logging systems in the co-operative general practices proved greater than that in social services. First, the practice managers had to be willing to assist. Second, the log had to be short, easily completed, and available in paper and electronic form with a reminder system attached. Help was offered by the research team with the installation of the templates. The problems to be overcome included a lack of uniformity in the information technology and paper systems used in the general practices, a reluctance

to add extra items over and above information routinely and legally required, and variation between practices from those that were “paperless” to those with only elementary electronic record keeping. The pulling together of information with patient consent from a range of sources was a very time-consuming research task. The quality and content of the logs completed in the practice and returned to us are very variable. Some data sets on individuals are partial because the records were returned to the Health Authority very soon after an older person had died. Some GPs gave full access to the records and had comprehensive notes on telephone calls and patient and carer contacts, as well as on hospital visits. However, few GPs routinely recorded contact with family carers, referrals to and communications with social services or the care packages received. This is in marked contrast to the position in social services where we found that letters from GPs, contacts with them, and with nurses and consultants were usually well-recorded and retained on the files.

Our logs for general practice make a start in developing ‘information capture’ frameworks for contacts with carers and social services for routine use in the audit of activity across the services’ interface. Large-scale development work seems to be required to promote more compatible and more integrated information systems and practices, particularly person-based systems with high quality data (Godden and Pollock, 1998) that permit documentation of client pathways and offer unified systems of case management (Hannigan, 1999). Potential differences of opinion between professionals about confidentiality would have to be considered.

Discussion

This paper has highlighted some of the difficulties associated with this type of research. First, it is our experience that there was no adequate sampling frame for the population under study in the two areas. The use of computerised record systems to select a sample of new referrals would be the preferred option. However, we found that where computer systems are in place, they do not always yield up-to-date, or relevant (to the study) information. As with other similar studies, samples had to be recruited through social workers. Our

experience demonstrates that social worker participation can be variable depending on the motivation, willingness and ability of the social workers to participate. This can lead to sample bias as the selection of the sample is influenced by the social workers.

To minimise this problem, future researchers may choose to select areas where one criterion is not just the availability of centralised computer systems, but where information on new referrals and social worker allocation is updated very speedily. This may be increasingly possible as information systems in social services are developing and improving rapidly. However, it is unlikely that this will overcome completely the variability in social worker participation. The enthusiasm of senior and first line managers for the research also goes some way to securing social worker participation.

Because of ethical requirements, our researchers could not approach older people to recruit them into the sample before they had been approached by their social worker and given permission to be contacted. As this part of the research depended on the social workers, recruitment into the sample was slow and target numbers had to be reduced. Future research needs to allow for the fact that this process can, at worst, take up to several months and include this in time planning and costs for the project.

Of those older people who were contacted, 35 per cent refused to participate. There is non-response in all surveys and this is a similar rate to other comparable research. There may be little scope to reduce this rate. However, 18 per cent of the older people who were eligible were excluded by social workers for health or family complications. One solution may be to agree very clear criteria for exclusions with the social workers at the outset of the study. Nevertheless, their professional judgement and the sensitivity of their work will always have to be respected and their continuing co-operation with the research team should not be jeopardised.

In any follow-up or longitudinal study, there needs to be a consideration of sample attrition. This is especially true with this group because of its age, and in our study thirteen per cent (10) had died by

six months after their first interview. Sixty three per cent (50) were re-interviewed. Although we gained information on outcome at six months after first interview for all but one of the sample from various sources, this is a factor that would need to be considered in planning a larger study. One possibility may be to redefine the population under study to cover a wider age range but it has to be recognised that the majority of older people using social services are aged 75 and over.

We have discussed the challenge of interviewing a respondent who shows signs of moderate or severe cognitive impairment, which in our study comprised over half of the sample. It is important to include this group in any larger scale study. In standardised interviews, the interviewers' side of the question and answer process should be entirely scripted so that questions are asked only of the respondents and in exactly the same way. This is not always possible when interviewing older people with dementia, and it is likely that some data on services will always have to be collected from other sources, raising the issue of reliability. We have highlighted the fact that even though older people with dementia were unable to complete a full interview in survey style, many were able to comment on services, provided they were listened to carefully (Reid et al, 2001). This supports the argument that the perspectives, values, and preferences of people with dementia warrant closer attention from clinicians, service planners and providers, and the research community (Gwyther, 1997), particularly because much research has been informed by the carer rather than the person with dementia (Stalker et al, 1999). From our experience with this study we agree with Woods that the perspective of the person with dementia, and outcomes reflecting that perspective, must be represented in research studies in dementia care (Woods, 2001).

Any future tracking exercise has to take account of the differences between social services and GPs in the way that contacts are recorded, as well as the amount of information perceived as necessary. Once social workers work alongside GPs and integrated primary and social care teams develop, integrated and shared information systems may become more common, making this part of the exercise easier to undertake. In planning any larger

scale project, it will be necessary to take account of the time-consuming nature of the tracking process on the part of the researchers.

Conclusions

In this discussion paper we have tried to give a comprehensive, descriptive account of the factors that affect research across the social and primary care interfaces, focusing on research which seeks to assess the outcomes of services for those that use them. Our experiences confirm that such research is complex, labour-intensive and time-consuming. Large studies to compare more than two models of collaboration will have to recruit large samples of service users with and without dementia, take account of changes in services and of variety within the dominant model in any area, and will require a longer time-scale and a large research team. Some of the component parts of this study stand alone but the service users' experiences and the outcomes of services will be understood and explained only partially without an in-depth and multi-faceted approach.

The move to Primary Care Trusts and later to Care Trusts may in time change the responsiveness of general practitioners to evaluation of joint working with social care, but significant problems in the documentation of information about social care in a standard and accessible form in general practice need to be addressed.

Correspondence to:

Dr. Steve Iliffe, Department of Primary Care and Population Sciences, RFUCMS, Royal Free Campus, Rowland Hill Street, London NW3 2PF.

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Appendix 1: The instruments used in the study

Information sheets for social services and general practices
Interview schedule for senior managers
Interview schedule for social services team managers
Interview schedule for social workers
Interview schedule for general practitioners
Form for consecutive assessments by social workers
Short form for consecutive assessments
Information sheets for older people and carers
Consent form for older person
Agreement form for carer (if older person unable to sign his / her own form)
Consent form for access to medical notes of older person
Time One Interview Schedule for Older Person including:
Mini-Mental State Examination (MMSE) (Folstein <i>et al.</i> , 1975)
Geriatric Depression Scale (GDS) (Yesavage <i>et al.</i> , 1983)
Lambeth Disability Screening Questionnaire (Charlton <i>et al.</i> , 1983)
General Satisfaction Questionnaire (GSQ) (Huxley and Mohamad, 1992)
Time One Interview Schedule for Carers including:
Lambeth Disability Screening Questionnaire (for older person)
General Health Questionnaire (GHQ - 28) (Goldberg, 1978)
MOS SF-36 General Health Survey (Ware <i>et al.</i> , 1992)
General Satisfaction Questionnaire (GSQ)
Form for ongoing tracking meetings with social workers including:
Social worker/older person or carer contact sheet
Social worker/GP contact sheet
Social worker/community nurse contact sheet
Notification of older person's death
Contact log for general practice (paper/electronic)
Medical records form
Time Two Interview Schedule for Older Person including:
Mini-Mental State Examination (MMSE)
Geriatric Depression Scale (GDS)
Time Two Interview Schedule for Carers including:
MOS SF- 36 General Health Survey
General Health Questionnaire (GHQ)

