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Recruiting patients into a primary care based study of palliative care: why is it so difficult?

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In the UK, researchers' access to study populations and control over selection of participants is becoming increasingly constrained by data protection and research governance legislation. Intervening stages placed between researchers and the population they wish to study can have serious effects on recruitment and ultimately on the validity of studies. In this paper we describe our experiences of gaining access to patients for a study of palliative care in primary care. Despite considerable time and resources dedicated to recruitment, a smaller than anticipated study sample was achieved. We found that gatekeeping by ethics committees and practitioner control over sample selection were significant hurdles in accessing patients for the study. Gatekeeping responsibilities represent considerable challenges for researchers seeking to obtain a representative study sample, not just in palliative care, but for research in general in health care. *Palliative Medicine* 2004; **18:** 452–459

Key words: ethics committees; gatekeeping; palliative care; primary care; recruitment

Introduction

The external validity of any study depends greatly on sample size and representativeness, as they determine whether any effect can be reliably demonstrated and findings generalized.[1] Yet researchers' access to patients, *qua* study populations, and control over identification and selection of patients, *qua* participants, is becoming increasingly constrained by data protection and research governance legislation found across Europe.[2] In the UK there has been considerable debate about implementation of the Data Protection Act 1998 and its effect on research access.[3–8] Under the provisions of the Act, intervening stages are placed between researchers and the population they wish to study. Multi-Centre (MREC) and Local Research Ethics Committees (LRECs) have responsibility for ensuring an ethical approach to patient recruitment in adherence with the Act and research governance directives.[3] This has resulted in health care professionals acting as gatekeepers for recruitment to research studies. While accepting the need for ethical safeguards, our experiences have led us to argue that these intervening stages have detrimental effects on recruitment and ultimately on outcomes and hence validity of studies.

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We have recently completed a study of palliative care in primary care, in which we recruited a smaller than anticipated study sample (Box 1). The study was funded at a time when there was increasing focus on primary care provision of palliative care.[10] Also in our favour, was interest from practitioners in the area,[11] based on positive feedback from earlier work.[12,13] The research team had experience and expertise from previous studies of palliative care and were well known both locally and more widely.[14–17] We were able to dedicate considerable time and resources to negotiating access to carry out the study, in meetings and presentations, with the assistance of many 'local champions' (details in Box 2).[18] However it

Symptoms and Needs Study in Primary Care

The focus of the study was the provision of palliative care in the community by members of the primary health care team (PHCT). Different perspectives on care provided were obtained from patients, their lay carers (*e.g.* next of kin), general practitioners (GPs) and district nurses (DNs). Study objectives included testing reliability and validity of the CAMPAS–R data collection tool which is described more fully elsewhere[9] and investigation of symptom assessments made by patients, their lay carers and health professionals. A key study question was 'How well do patients and primary care professionals agree on symptom assessment in the home care setting?'

Box 1

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Stakeholders	**Local champions**
Primary Health Care Teams	Health Services Research Group
Directors of Palliative Medicine	Team members local GP/researcher Nurse researchers in Palliative Care Nurses from practice Hospice Medical Officer
Directors of Clinical Oncology	
Oncology Services Managers	
Hospice Consultants	Professor of Health Services Research / Regional Director of R&D
Trust Directors of R&D	Professor of General Practice
Nursing Managers: hospital and community based	Lecturers/Facilitator in GP & PCRU
Clinic Managers	GP and DN participants in previous projects
Non−oncology Hospital Departments	Nurse managers from previous studies
	Consultants / research collaborators
	Macmillan Nurses / research collaborators

Box 2

was gatekeeping by ethics committees and by practitioners that appeared to have the greatest effect on study recruitment. In this paper we focus on this aspect of the recruitment process and its outcomes in order to unpack the effect on research validity. Then we discuss the perspective on gatekeeping gained from the study and consider implications both for researchers seeking access and indeed for participants in the research process.

Methods

Study sample

Patients eligible for the study were adults in the palliative phase of a progressive illness, being cared for at home and who were estimated to be in their last year of life. Palliative care is most commonly associated with cancer, but we also included patients in the palliative phase of other illnesses such as end stage respiratory, renal or cardiovascular diseases. Participants were asked to remain in the study for up to four weeks of data collection. On this basis, it was inappropriate to include patients whose prognosis was estimated to be less than two months. Two further exclusion criteria were any major psychiatric disorder and patients who were unable to complete data collection forms without help. When patients had agreed to participate, lay carers (e.g., spouses) were then recruited to the study.

Our calculated sample size was 200 patients, the number required for the analysis of validity and subgroup analysis we wished to conduct.[19] There were approximately 400 GPs in practice in the recruitment areas, each of whom one would expect to have five patients each year dying from cancer and 14 dying from a noncancer diagnosis.* On this basis, with a two-year period planned for recruitment, it seemed feasible to obtain the required sample from primary care alone. However, recruitment was extended to secondary care for methodological reasons. As well as being asked to recruit patients for the study, GPs and DNs themselves were part of our target population. We therefore included secondary care recruitment to extend the range of primary health care teams represented in the study to reduce recruitment bias from a self-selecting sample.

Primary care recruitment

We wrote to GPs and DN teams approximately every two to three months to ask them to identify suitable patients for the study from their practice. The process was kept as simple as possible to encourage their assistance (Box 3; Phase 1). Practitioners were free to discuss the study with prospective patients if they wished, but written consent from patients to pass on their details was not part of the recruitment process. On receipt of contact details, the research team called patients to arrange a meeting to explain the study further, at which time written consent was obtained if they decided to take part. The recruitment procedure was approved by the relevant LRECs.

This procedure for primary care later had to be revised for MREC application to extend recruitment to a wider study area. To meet the requirements of the Data Protection Act (1998), implemented in March 2000, we

* These figures are based on an average GP list size of 1900 patients and figures of 2800 deaths from cancer and 6900 from nonmalignant disease per 1 000 000 population in England each year.[20]

Primary Care Recruitment; Phase 1	Primary Care Recruitment; Phase 2

Letter about study to GPs and DN teams with
• Information sheet of study requirements
• Recruitment form
 	
Patient details returned to research team
GP consent for research team to make contact with patient
	Letter about study to GPs and DN teams with
	• Information sheet of study requirements
	• Covering letter from GP/DN to patient about study
	• Stamped envelope for letter to patient from GP/DN
	• Recruitment pack containing
	  • Study Information Letter for patient
	  • Reply form for self disclosure of patient contact details
	  • Freepost envelope for return
	
	Letter and recruitment pack to be sent to patients
	Patient returns form to research team

Box 3

needed a formal procedure for gaining patient agreement for contact details to be passed to the research team. For MREC, the requirements were clear. We had to ask health professionals to pass details about the study on to patients, so that patients themselves contacted the research team if they wished to take part. With primary care recruitment we found ourselves in a 'Catch 22' situation. We were not allowed access to contact details of suitable patients without their prior agreement, but there was no mechanism for gaining their agreement without knowing who they were in the first place. To overcome this problem we asked PHCTs to forward recruitment packs to potential patients who then replied directly to the research team if they wished to take part (Box 3; Phase 2).

Secondary care recruitment

We had assistance with recruitment from Oncology Departments and Palliative Care Teams. Nononcology services including renal and chest medicine, cardiology and medicine for the elderly also agreed to take part. Initially consultants provided names and contact details of potential patients for the study, in a similar procedure to primary care professionals (Box 4; Phase 1). Recruitment was subsequently extended, to increase patient numbers, to Oncology Clinics where potentially eligible patients were seen on a regular basis. A more 'hands on' approach was adopted to facilitate the recruitment process. Honorary nursing contracts were arranged in two hospitals for team members (GE and MR) who attended clinics and liaised with staff, but did not have direct contact with patients. The form for obtaining patient contact details was revised to a study information letter which clinic nurses and doctors gave to eligible patients.

At this stage, consent of the GP who was responsible for the patient's care was obtained before any approach was made to patients. GP agreement was included because we were not only recruiting patients, we also needed members of the PHCT to take part whenever they had a patient contact. We hoped to facilitate their participation by having their permission to include their patients in the study. It was also anticipated that home circumstances might be less well known in secondary care, and GPs were asked to review patients' eligibility. LRECs approved the recruitment procedures.

During recruitment in clinics we found that we were unable to approach all potential patients about taking part. As a community-based study, we were advised that we could only include patients if we had approval from the LREC in whose boundaries their GP practice was situated. As we were recruiting in a Regional Centre, patients came from many different areas, each with a different LREC. To gain access to these patients necessitated a MREC application and subsequent LREC applications, which was time consuming and caused considerable delay to recruitment. The procedure approved by MREC was the one already in place for clinic recruitment, except they advised that there was no requirement to seek the GP's consent, only to notify practices when patients took part (Box 4; Phase 2)

Results

Primary care outcomes

There were 12 recruitment rounds, between August 1999 and October 2001, in which 1871 individual contacts were made with GPs and DN teams. This resulted in identification of only 78 potential patients, in total, from

Secondary Care Recruitment; Phase 1	**Secondary Care Recruitment; Phase 2**
Secondary care sources have • Information sheet of study requirements • Recruitment form Patient details returned to research team GP agreement before contact with patient *Modification of procedure for clinic sources* • Study information letter for patient instead of Recruitment form	Secondary care sources have • Study information letter for patient • Reply form for self disclosure of patient contact details • Freepost envelope for return Patient returns form to research team GP notification of patient participation

Box 4

primary care professionals (Table 1). The proportion of patients identified differed in the two recruitment phases. In Phase 1, with the original simplified recruitment design, 5.2% (95% CI 4.0–6.5) of requests resulted in patient nominations to the study. With the more complex Phase 2 procedure put in place after MREC application, only 1.8% (95% CI 0.9–3.3) of contacts resulted in patient nominations. There is a significant difference between patient identification rates in the two phases (difference in rates = 3.4%; 95% CI of difference = 1.6–4.9).

Secondary care outcomes

A larger number of patients were identified through secondary care (239) than through primary care (78) (compare Figure 1 with Table 1). However, participation in the study was not significantly different from that in primary care (50.3% in secondary care, 51.4% in primary care). Access to many patients was lost at an earlier stage in the recruitment process, because they lived out of area or we did not have their GP's consent to approach them.

Out of area. During clinic recruitment we found that many patients could not be considered for the study because they lived outside the areas for which we had LREC approval. We monitored clinic lists for out of area cases for a six-month period during which our application was made to MREC to extend the study area. Access was lost to at least 90 potential patients. In addition a further 22 patients (one in primary care and 21 from secondary care) were cases passed on to the research team as eligible for the study, but living out of area.

No GP consent. We were unable to access a further 46 patients because we did not have their GPs' permission for them to take part. Ten of these patients had been given a study information letter and had replied indicating they wished to take part. Although we sent signed agreement forms from patients to their GPs, we were unable to obtain permission to include these patients in the study (GP consent was part of the study protocol at that time). In another seven cases we had no response from GPs, either to initial letters seeking agreement or to follow-up contacts. The remaining 29 GPs responded and we reviewed the comments received.

Ten GPs cited ineligibility criteria that would have excluded these patients from the study. Another six described patients as 'unsuitable', for example: 'I am

Table 1 Recruitment of patients through primary care

	Contacts by letter	Patients identified	Ineligible/out of area	Patients approached to take part	Patient declined	Participation in study
Phase 1	1314	68 (5.2%)	7	61	31 (50.8%)	30 (49.2%)
Phase 2	557	10 (1.8%)	1	9	3 (33.3%)	6 (66.6%)
Total	1871	78 (4.2%)	8	70	34 (48.6%)	36 (51.4%)

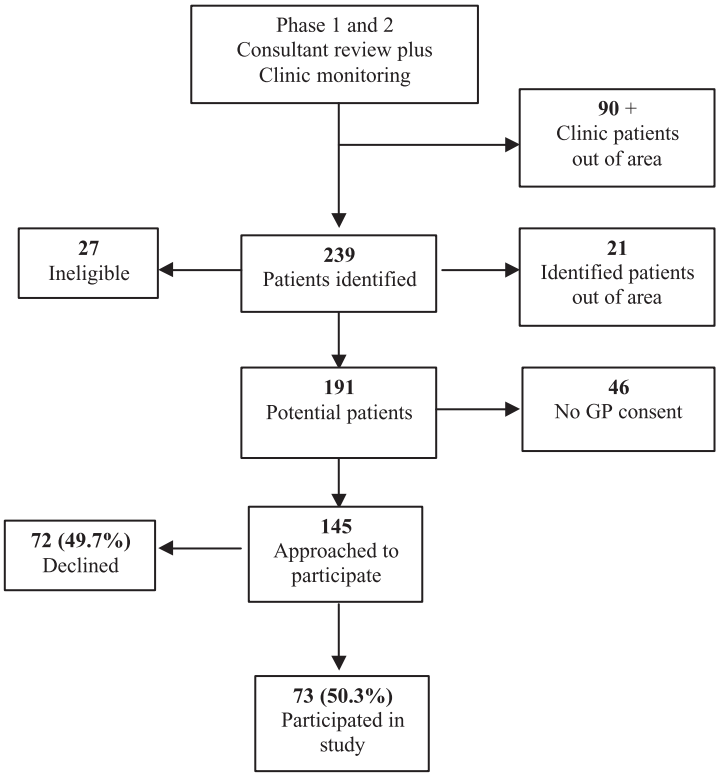

Figure 1 Accessing patients through secondary care.

afraid I do not think he is a suitable patient for your research project and therefore cannot give my consent to you approaching him at his home.' but didn't mention any exclusion criteria. Five GPs appear to have acted on behalf of patients, such as: 'Although I haven't seen [patient] for a few weeks I am fairly sure he would decline to join your home care study.' Others acted for patients for particular reasons such as their physical condition, 'He is going downhill' or because of concerns about anxiety and upset, 'He and his wife are very, very anxious and I think would be made worse by extra 'fuss and attention'. I therefore do not think it would be appropriate to approach them.'

In the remaining eight cases, access was lost for reasons unrelated to concerns about patients *qua* individual participants in the research study. Patients were registered with practices that had decided not to take part. Pressures of time and increased workload reportedly prevented some practices from participating. In this context, the question of reimbursement of their time spent on the study was raised. One of their GPs wrote: 'As you are no doubt aware GPs are under ever increasing pressure from many different sources. In these days of evidence based medicine we are asked to take part in more and more research studies. Nice as it would be to co-operate with everybody this is not possible without appropriate resources.' Another practice questioned the value of the study, in response to a request for GP agreement for one of their patients to take part. As they did not reply to subsequent requests we were unable to access any of their patients.

Discussion

Palliative care is known to be a difficult area for research[21–24] and there are added problems with recruitment of patients to studies in primary care.[25–27] At the outset of the study we anticipated that, even with the most careful approach, patients and their families might not wish to take part in research when they were facing a life-limiting illness. What we had not adequately anticipated was the difficulty we would have in gaining access to patients in the first place, to ask them to take part. Adequate time and resources were dedicated to negotiating access[18] and requests for assistance with accessing patients came from practitioner colleagues, a positive strategy in improving response rates.[28–30] Yet efforts made with recruitment were disproportionate to the outcome we achieved. However, our experiences have highlighted additional gatekeeping hurdles from ethics committees and from practitioner-led access, which are important considerations not just for palliative care studies but for research in general in health care.

Research teams are dependent on approval of ethics committees to proceed with recruitment to a study.

Therefore they need to be confident that advice provided is both well founded and consistent. In discussions with research colleagues and the relevant LREC administrators, the basis of advice we had on out of area subjects remains unclear. Other studies that included data collection in the community do not appear to have had the same restrictions. Furthermore, advice given to those recruiting for clinical trials in secondary care is that they need approval only from the LREC where the hospital is located, regardless of where the patient lives (personal communication with LREC administrator). Lack of consistency in advice on interpretation of the Data Protection Act is also a concern.[6,31] The Anglian MREC's interpretation of the Data Protection Act resulted in a loss of access to patients. The simplified procedure thought to encourage participation from GPs[32] had to be replaced with a more complex one which had a negative effect on recruitment as we have shown. Other studies have used the same approach to recruitment, with ethics approval, that was rejected by Anglia MREC when we applied.[33] Since recruitment to the study was completed, there has been new guidance given to NHS Research Ethics Committees.[34] The new COREC arrangements promise greater standardization and clarity with the requirement of fewer applications.[35]

Workload pressures in primary care are obstacles in practitioner-led access to study patients.[26,36] We heard both formally and informally from PHCTs that in the climate of change in primary care, there were too many other demands on their time. With these constraints and a choice to be made between clinical work and assisting with research, their priority was clinical practice. In future studies, strategies to promote participation will have to be considered, as researchers are unlikely to be able to rely solely on co-operation and goodwill of professional colleagues to achieve access to sufficient numbers of study patients. Payment for participation, which was not an option included in the research budget of the present study, has been shown to have a positive effect on response rates from GPs.[37] Reimbursement for systems with recruitment may go some way to resolving workload-related problems of access.

The issue of ownership is a further hurdle in accessing patients for primary care studies. Even where the subject area is relevant to practitioners, a factor that promotes participation,[11] low patient numbers in primary care are problematic to commitment to a study. With palliative care, for example, a GP will have only a few patients each year to care for at home. Extending recruitment for primary care studies to secondary care may permit access to greater patient numbers, but ownership is clearly more of a problem. To avoid practitioners being used as 'mere conduits to reservoirs of people on their lists',[38] one way forward is more partnership between research teams and health professionals in practice and this was a strategy we started to explore in the present study. To promote collaboration with clinic nurses involved in recruitment, the team offered research training sessions to meet the needs of nursing staff. Similar reciprocal arrangements may promote co-operation with primary care teams, but these additional costs will have to be included in research budgets.

Finally, there are concerns about practitioner-led access, where not all eligible patients are approached to take part.[7,25,26] Our qualitative data on GP consent suggests that practitioners appeared to face a dilemma in the recruitment process. They recognized a need to be supportive of research, but on the other hand they felt the need to act on behalf of patients being recruited as well as to protect their own clinical priorities. GPs sought to protect patients, expressing concerns about possible anxiety and upset for families and, on occasion, designating our contact as 'not appropriate' when asked for their agreement to approach patients about the study. Practitioners in secondary care did not approach all eligible patients for similar reasons. Such dilemmas are 'the stuff of everyday life' and everyday clinical practice[39] but whilst they no doubt believed their actions were doing good rather than harm, what Freidson describes as the clinical mentality of practitioners,[40] there are detrimental consequences to their actions. The effect of health professionals taking on this responsibility for protection is clearly one that causes sample bias. Furthermore, however well intentioned the action of professionals, for patients there is a loss of autonomy which, ironically, data protection legislation was seeking to provide in the first place.

If there is more partnership in the future between practitioners and research teams, roles and responsibilities in patient recruitment and their effect on study samples will be an important area to be addressed in any potential collaboration. At present in the UK research governance directives are if anything driving an even greater wedge between researchers and the clinicians and clinical populations they research, exacerbating rather than ameliorating the problems outlined in this paper. Whilst we recognize and indeed support the new requirements, we believe there must be a mechanism to balance the needs of such regulation with the needs of scientific rigour and validity, so that researchers can conduct high quality research with patients who represent the broad spectrum of disease and experience.

Conclusions

Researchers seeking access to a study population in primary care face considerable challenges if they wish to obtain a representative sample. The demands of a primary care led NHS and requirements of research

governance represent significant hurdles to be negotiated in accessing study populations. If high levels of contact are required with PHCTs to gain their co-operation with primary care research, then there is a real risk that studies are going to be conducted with smaller groups simply to ensure access to potential participants. The Data Protection Act 1998 and its interpretation by ethics committees already prevents researchers having knowledge of their sampling frame, i.e., the study 'denominator' remains unknown. Furthermore, with recruitment regulated solely by health professionals, the 'numerator' will also be affected every time they do not pass on study information details to an eligible patient. The overall effect is that researchers will be unable to give any evidence of the representativeness of their study samples. In future studies, if researchers wish to ensure access to study populations, research proposals will need to take account of these challenges to recruitment, with additional resources in research budgets dedicated to payment or other reciprocal arrangements that promote collaboration between research teams and practitioners.

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