

# 'Will you help me with my research?' Gaining access to primary care settings and subjects

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**SUMMARY.** *This paper is concerned with the negotiation of agreement to carry out research in primary care settings. It is argued that this is a key part of any research project, and that careful handling of this process will not only improve response rates, but will also often enhance the quality of the data obtained. A number of strategies for negotiating access are proposed which have been developed and applied in primary care settings. These strategies depend on creating a sense of collective ownership of projects between researchers and participants which contributes to the successful completion of the projects and provides a positive atmosphere for further collaboration.*

**Keywords:** *research setting; informed consent; interprofessional relations; interpersonal relations; research in general practice.*

## Introduction

**A**LMOST all research in primary care involves the important step of negotiating access to research settings or subjects. Such negotiation may be complex and demanding,<sup>1</sup> or it may simply be a matter of recruiting one's own patients or colleagues for a research study. Access may require little participation, such as asking general practitioners for permission to audit their patient records, or to use a disease register to identify patients who fit the entry criteria for a research study. Other studies might require more active cooperation. They might, for example, involve the observation of consultations, the allocation of patients to a particular treatment group, recording prospective data, taking part in research interviews, or introducing experimental systems of care for research purposes.

The importance of access negotiations are discussed widely in the literature, particularly that drawn from social science and education.<sup>2-5</sup> Whatever the complexity of the negotiating process, getting this step wrong may lead to projects failing or being compromised. The potential obstacles to gaining the voluntary participation of doctors are discussed at length by Borgiel and colleagues,<sup>1</sup> in relation to the methodological implications of low participation rates in research projects. We would argue that the quality of access obtained is as important as the quantity. Half-hearted or ill-informed consent may enable one to get the project underway, but participants may well withdraw once the implications of the project become clear. Even where they do not actually withdraw, lack of commitment, or a sense of

unease about the project, may compromise the quality of the data obtained.

Research studies also vary in terms of the number of people who will need to be involved in access negotiations. At the simplest level, arranging an interview with an individual general practitioner will rarely involve more than gaining the agreement of that one individual. However, if a piece of research involves a whole general practice team, it will be important to secure the support of the whole group. Where the research initiative extends beyond individual practices, negotiations may need to take place not only within practices but at a district or even regional level, and could involve the family health services authority, the district health authority, hospital consultants and nurse managers.

Over the last five years we have collaborated with a management consultant and other members of a multidisciplinary research team to plan systematic strategies for gaining entry to a range of research settings of the types described above.<sup>6-8</sup> Throughout this collaboration, we have sought to minimize the possibility of the research projects being obstructed by misinformation or inadequate consultation, and to negotiate access in such a way that agreements reached initially are sufficiently robust to be sustained throughout the study. The strategies which we used are summarized as follows:

- Identify stakeholders (participants/those with external interests).
- Consider stakeholders' potential response to the project.
- Consult external stakeholders where appropriate.
- Identify gatekeepers.
- Identify local champions.
- Supply adequate and appropriate information.
- Contact gatekeepers.
- Negotiate (avoid irrational refusals/slow down premature agreement).
- Ask for cooperation and make practical arrangements.

## Gaining relevant background information

The first step in planning the negotiation of access is to identify all those who have a 'stake' in the project (stakeholders). These are individuals or groups who might be affected by the proposed research, or have some kind of investment in it, and may have the power to promote or obstruct the project. It often takes both imagination and investigation to discover who these stakeholders are. Broadly they can be thought of as falling into two groups: those who will be directly involved in the research process (participants) and those not directly involved but whose support may be important (external stakeholders). The most easily identifiable participants include those being interviewed or observed, and those who are asked to collect data or take part in experimental systems of care. In addition, there may also be participants who, while not involved at this practical level, may be in a position to support or obstruct the research. For example, if the data to be collected includes videotapes of interactions between practice nurses and patients, the agreement of both groups would be needed. However, without the support of the general practitioners and the cooperation of the reception staff, the success of such a project could be jeopardized.

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External stakeholders might include the general managers of the family health services authority and the community unit of the district health authority, the district department of public health, relevant hospital consultants and nurse managers, postgraduate general practice tutors, and the local medical committees. People are often more comfortable with interventions when they are supported by opinion leaders and powerful members of their community. Negotiating the support of such people and organizations at the outset will often ease access to individual research settings.<sup>1</sup>

Having identified all the participants and external stakeholders in the research, it is helpful to consider their likely response to the research proposal. The following questions should be reflected upon in this context:

- What is this individual/group's current involvement in the proposed research setting?
- What might the benefits of the research be to this individual/group?
- What might the costs of this research project be to this individual/group? Such costs might include time, disruption, financial loss and exposure.

- What power does this individual/group have to affect the success of the research adversely?

Where the number of participants or external stakeholders is limited to one or two, this information can simply be listed for each. However, where many people are involved, the data generated in response to these questions can be unwieldy. A device known as the domain map,<sup>9</sup> which was originally developed in industry to organize complex information and support the development of helpful strategies, has been adapted for use in general practice.<sup>7</sup> This domain map is made up of five concentric circles around a central core. The first circle is used to list the individuals or groups with a stake in the proposed research. The other four circles relate to the questions set out above. Figure 1 demonstrates how the domain map can be used to organize and display the data generated by applying these four questions to the participants in a particular research setting. In this research project a facilitator sought to gain access to a number of different individuals and groups within local general practice teams in order to set up systems of structured diabetes care (Spiegel N, *et al.* Unpublished results). A similar domain map was drawn up at an early stage of this project,

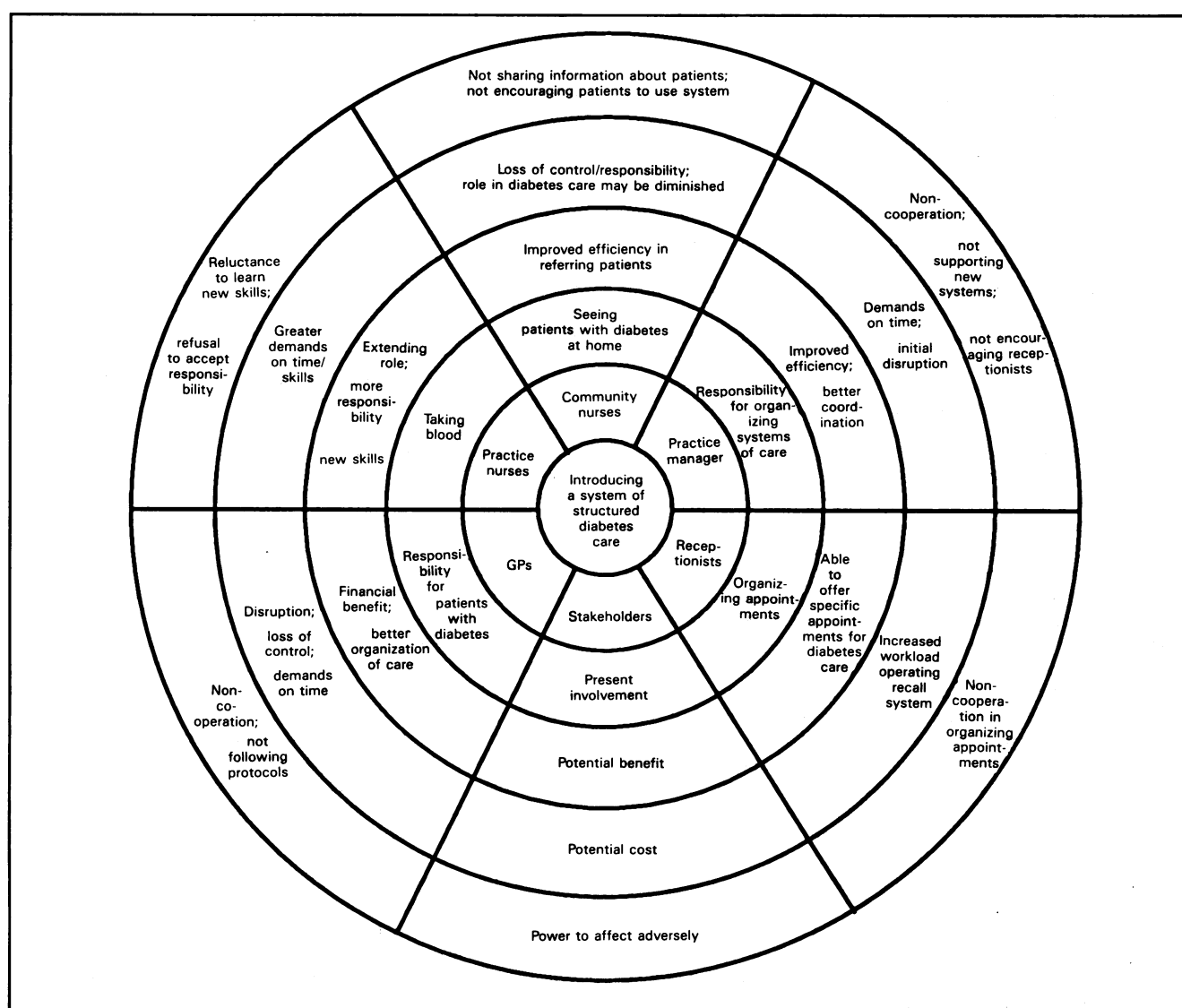


Figure 1. Domain map used to display information relevant to a study of the role of a facilitator in setting up systems of structured diabetes care.

to organize the available information about external stakeholders.

This information, whether in the form of a list or a domain map, gives a clear indication of the feasibility of the proposed research, and enables the researcher to identify particular groups who might support the research initiative and also those who may obstruct it.

### Strategic planning

Having identified the range of stakeholders in relation to a particular project, and considered their possible perspectives, the next step is to initiate negotiations.

Where external stakeholders have been identified, it may be helpful to consult them before research plans are finalized. Such early involvement has a number of advantages. External stakeholders may have an overview of the research setting, an awareness of practical constraints, and access to resources which could be made available for the research. At this stage, it may also be possible to build ownership and commitment to the research among stakeholders by exploring ways in which it can be of direct benefit to the groups they represent. If such ownership and commitment is generated at an early stage, support by the stakeholders is more likely to be sustained in the face of any difficulties which arise in the course of the project.

### Identifying gatekeepers

Where a research project requires the cooperation of a number of people who work together, an important early decision concerns whom to approach first.<sup>2,5</sup> Approaching the wrong gatekeeper can have long-lasting detrimental effects on the whole project. As with any organization, general practice teams can experience conflict and factional dissent, and gaining entry through one group or individual can obstruct the researchers in their dealings with other groups or individuals.<sup>4</sup> It may be necessary to consider the possibility of approaching two or more groups within a research setting simultaneously. The usefulness of this procedure, known as 'dual' or 'multiple' entry,<sup>4</sup> was demonstrated in the project evaluating the role of a facilitator in setting up structured diabetes care (Bain DJG, *et al.* Project report to Nuffield Provincial Hospitals' Trust, 1990).

This project involved setting up a meeting with whole practice teams. The initial step in setting up this meeting was to make contact with one member of the practice team within each practice, and it was necessary to decide who should be approached as gatekeeper in this context. For many of the practices the idea of a meeting to which the whole team was invited was new and a threat in itself. To begin with we made the assumption that the practice manager was the appropriate channel for such requests. However, subsequent experience revealed a number of problems with this approach.

First, we discovered that while, in theory, the practice managers were the organizational heads of the primary care teams, in reality they had very little power to negotiate on behalf of doctors. In most of the practices we approached, there was no precedent for meetings of the whole practice team and the practice managers had little power to instigate such a meeting. However, it is generally seen as part of the practice manager's remit to protect the doctors from unsolicited approaches, and so refusing access could be seen as a legitimate course of action. Thus, the power which they had was often negative rather than positive, and meant that, while they were able to obstruct access, it was much more difficult for them to grant it.

Secondly, a project primarily concerned with the management of change in practice teams might be expected to have a radical impact upon the work of the practice manager. By treating the practice manager as gatekeeper we were approaching the one person who was most likely to be affected by the innovation and

asking him or her to become the advocate of the project within the practice. The practice managers had much to gain from the study because of the particular management skills which the facilitator could offer to them, but they needed time to appreciate this for themselves, rather than asking them to act as if they believed it from the outset.

As a result of early difficult experiences, we changed our approach. We decided to approach the practices at two levels simultaneously. Practice managers were contacted, introduced to the project, and asked for their reactions to it. They were not expected to negotiate with the doctors on our behalf. At the same time we wrote directly to the doctors, explained the project and negotiated agreement to the team meeting. In this way we avoided going over the heads of the practice managers.

### Negotiation with individuals

In the case of negotiating access with individual participants, it is helpful to find a 'local champion',<sup>1,2,10</sup> who is prepared to introduce the researcher to the participants. This local champion could well be one of the external stakeholders or simply a respected member of the professional community. Where the researcher has had no previous contact with those being approached, this is particularly important.

Those with whom access is being negotiated need adequate information about the proposed research before being asked to decide about their participation.<sup>1,3,5</sup> As Burgess<sup>3</sup> points out this information should not take the form of a 'theoretical treatise', but should be accessible to the recipients. The focus should be upon the practical implications of the research for those who would be involved in it.

In a current interview study involving doctors and their patients, a one-page summary of the research was sent to general practitioners, prior to a meeting to discuss participation (unpublished results). The main areas covered by the summary were the aims of the research; the credentials of the researcher; the demands which the research would make upon doctors and their patients; the ethical implications of the research; and the anticipated benefits of the study. It is important not to overload potential participants with information and such a summary should be limited to important elements of the project, such as the amount of time which would be involved.

Having sent such a summary, the next step is to make personal contact, either by telephone or face to face. While it is important to acknowledge that people may have rational reasons for refusing to participate in a research project, it is also true that agreement can be obstructed by suspicion, lack of adequate information or inaccurate assumptions. A central objective in initial discussions, is to avoid irrational refusals.

We developed a strategy for handling such a negotiation with general practitioners in the interview study, discussed above. Having established that it was a convenient time to talk, the negotiator started with a very open question: 'Do you have enough information to make a decision about being involved?' It is important to offer an opportunity such as this to clarify any points arising from the summary and to ensure that decisions are based on adequate and accurate information. We also wanted general practitioners to be able to express concerns without feeling under threat and therefore took the initiative in exploring any reservations they had about the study. We were anxious that their reservations should be openly discussed rather than exercising hidden control over their decisions.

As well as avoiding irrational refusals, we also wanted to prevent premature agreements. In a study which needs long-term cooperation from participants, it is essential to arrive at a robust commitment which will last when the novelty has worn off and the project may be conflicting with other demands on time and

interest. Where doctors claimed that they had no reservations, we took the initiative in drawing potential difficulties to their attention. Our experience has been that agreement reached in the light of clearly acknowledged difficulties is much more robust than agreement which is reached without a thorough consideration of the potential costs.

The next step was to ask specifically for cooperation. If the doctor agreed, practical arrangements were then made. If not, a final attempt was made to discover what particular problems the study posed for the doctor. The question, 'We are anxious to know if there are aspects of this study which make it difficult for people to participate. Could you tell me what in particular makes it difficult for you to agree?', proved to be particularly useful.

### Conclusion

Fundamental to the approach outlined here is the belief that the quality of the access negotiated has a direct effect upon the quality of the eventual research data. Good quality access also minimizes the risk of cooperation being withdrawn at a later stage when considerable time and effort has been invested in the project. Moreover, quality access leads to a sense of collective ownership of the project, both in its teething problems and its eventual outcome, and it is thus more likely to be successfully completed and to leave all the participants with a sense that involvement in research is a positive experience.

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