

Research Governance and its Implications for Housing Studies

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Abstract

The ethics of studying vulnerable individuals have up to now been left largely to the integrity and professionalism of individual housing researchers, with very few of them having to deal with formal ethics committees. However, this may be about to change because of the introduction of a Research Governance Framework by the Department of Health. Using a current qualitative research project as an example, this paper examines the significant implications of this change for researchers, funders and commissioners.

Introduction

Housing researchers are increasingly studying vulnerable individuals as a result of the trend towards the residualisation of social housing, which links to such issues as homelessness, rent or mortgage arrears, domestic violence and disrepair. This is particularly true of those carrying out research on the housing and care interface in relation to older people and others who may have support needs. Up to now how best to handle this has been left largely to the integrity and professionalism of individual researchers with very few of them having to deal with formal ethics committees. However, this may be about to change because of the introduction of a Research Governance Framework by the Department of Health, which will have a significant impact upon all housing research which requires interviews with service users or staff of the NHS and Social Services. Concern about the practical implications of this for researchers working in such areas as older people and housing has been expressed by Tinker (2001) on behalf of the Economic and Social Research Council's Growing Older Research Programme.

The Research Governance Framework

The initial draft of the *Research Governance Framework in Health and Social Care* was produced for discussion by the Department of Health (2001a) in March 2001 and revised versions have been published (Department of Health, 2003a) The framework covers all the responsibilities of the Secretary of State for Health, both in terms of the National Health Service and in terms of the social care duties of social services authorities. Full implementation for the NHS will take place in 2004 with the implementation timetable for social care under discussion (Department of Health, 2003b). However, it is crucial to realise that much of the framework and

especially that relating to ethical clearance is already operational in the NHS.

The justification given for the Framework is the need 'to prevent poor performance, adverse incidents, research misconduct and fraud, and to ensure that lessons are learned and shared when poor practice is identified' (DH 2001a, p4). This is to be achieved by the setting of standards, the defining of mechanisms to deliver standards and through the establishment of monitoring and assessment procedures to ensure that all of this takes place. Below we describe the implications of this in terms of the need for NHS ethics clearance irrespective of whether respondents are patients or staff. However, before this is carried out, it is important to stress that the governance standards go much wider than individual researchers presenting their application for ethics review. Rather governance is seen as being a quality issue for all those who participate in research including those who undertake research, those who manage research, funders of research proposals and organisations who host research.

The Figure below sets out the view of the discussion document about the key responsibilities of the main stakeholders. The research sponsor is 'the organisation taking primary responsibility for ensuring that the design of the study meets appropriate standards and that arrangements are in place to ensure appropriate conduct and reporting' (p20). The Framework assumes the sponsor will normally be the funder although the funder can delegate this to another organisation such as the employing organisation of the researcher. The need for a sponsor also applies to student undergraduate, postgraduate and doctoral research which carries significant implications for universities.

Figure 1

SUMMARY OF KEY RESPONSIBILITIES OF PEOPLE AND ORGANISATIONS ACCOUNTABLE FOR THE PROPER CONDUCT OF A STUDY	
Principal Investigator and other researchers	<ul style="list-style-type: none"> • Developing proposals that are ethical and seeking research ethics committee review • Conducting research to the agreed protocol and in accordance with legal requirements and guidance e.g. on consent • Ensuring participant welfare while in the study • Feeding back results of research to participants
Research Ethics Committee	<ul style="list-style-type: none"> • Ensuring that the proposed research is ethical and respects the dignity, rights, safety and well-being of participants
Sponsor	<ul style="list-style-type: none"> • Assuring the scientific quality of proposed research • Ensuring research ethics committee review • Ensuring arrangements in place for the management and monitoring of research
Employing organisation	<ul style="list-style-type: none"> • Promoting a quality research culture • Ensuring researchers understand and discharge their responsibilities • Taking responsibility for ensuring the research is properly managed and monitored where agreed with sponsor
Care organisation/ Responsible care professional	<ul style="list-style-type: none"> • Ensuring that research using their patients, users, carers or staff meets the standard set out in the research governance framework (drawing on the work of the research ethics committee and sponsor) • Ensuring research ethics committee review for all research • Retaining responsibility for research participants' care

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Source: Department of Health (2001a), p.21

However, there is no doubt that 'managing' ethics review will remain a key concern for researchers affected by the Framework. The primary responsibility of research ethics committees (RECs) 'is to ensure that (all) research respects the dignity, rights, safety and well being of individual research participants' (p33). All research in the NHS must have a prior positive review by an NHS research ethics committee which provide independent peer review and the performance of which are monitored by the NHS. The emphasis upon participant rights mean that NHS RECs place a high emphasis upon the written research consent

of all participants with participants having access to clear information sheets about the research. NHS RECs expect researchers normally to provide details of all research questions they expect to ask (Department of Health, 2001b).

So can all of this be made to work when housing research involves respondents covered by the DH Framework? Below is a case study which illustrates that it is complicated but that it can be made to work.

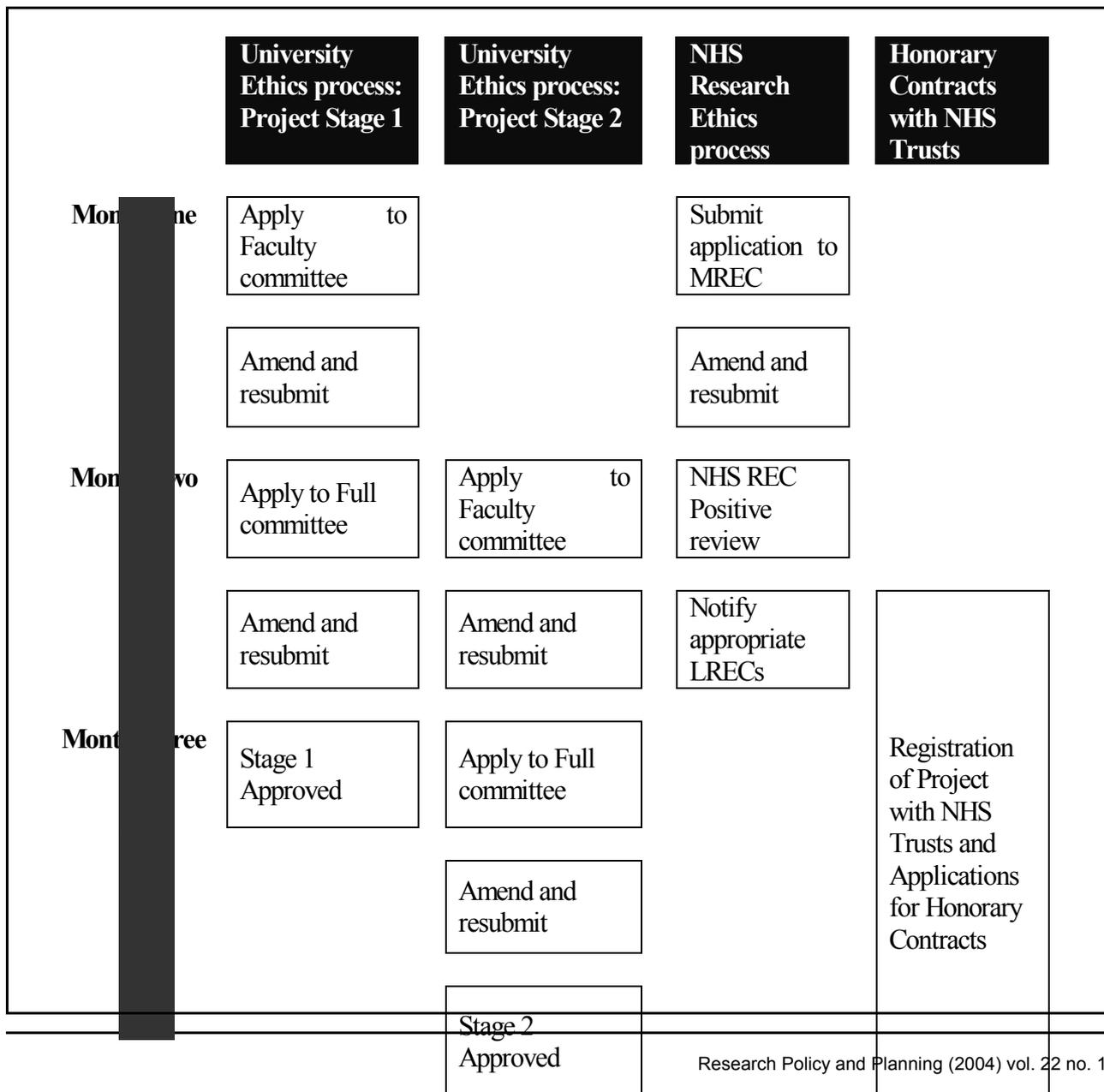
Making it Work: A Case Study

Researchers at the University of the West of England, Bristol (UWE) were commissioned to carry out a three year qualitative study of the suitability of very sheltered housing (1) (VSH) for people with dementia (2). This study focuses on six housing schemes in various parts of England and involves semi structured interviews with a range of stakeholders including housing scheme staff, health and social care professionals, people with dementia, their relatives and other tenants.

The overall ethical review and honorary contract application process can be divided into four parts, as outlined in the diagram below:

1. Full NHS Research Ethics Committee Review

The first question to consider was ‘Does this research require NHS Research Ethics Committee review?’ This is not always as straightforward as it sounds and in this case the answer was both yes and no. The key issue here is whether participants are being recruited to the study on the basis of their status as health service users or employees. This was indeed the case for the health and social care professionals taking part, but the other participants were recruited for different reasons: some as employees of a housing association; some as private tenants of a housing association; and others as relatives of those tenants. Therefore, only the part of the study that involved interviews with health and social care professionals required NHS



Research Ethics Committee (REC) review. Because the research was to be carried out in six research sites, an application was made for Multi Research Ethics Committee (MREC) review. Although only part of the study needed to be approved, as outlined above, it was not possible to describe the research in a meaningful way without including details of the entire study. The application therefore included details of the entire project but specified that review was only being requested for the interviews with health and social care professionals. This caused some confusion among members of the MREC and led to the lead applicant being invited to attend the appropriate part of the committee meeting to explain the situation. Their positive review was received, subject to minor amendments to the project information sheet and on reassurance that the other parts of the study would be subject to ethical review elsewhere (see below).

2. Locality NHS Research Ethics Committee review.

Most MREC positive review comes with the proviso that locality review must also be sought from all Local Research Ethics Committees (LRECs) in whose area the research is being carried out. However, in this study all the research was being carried out by one research team from the same base. The application was therefore scrutinized by the MREC on a 'no local researcher' basis. This means that there are no locality issues to be addressed and, having received full MREC review, the researchers only need to notify the appropriate LRECs of the research that will be carried out in their area.

3. University Ethics Committee review.

Increasingly universities have their own ethics committees to cover human subject research, and this is the case at UWE. Because of the timescale to which the researchers were committed, and the fact that only part of the project needed NHS REC review, it was decided to apply for University ethics review in two stages. Approval to interview just the managers of the six housing schemes was sought initially. Review of the proposal to the remaining interviews (with health and social care staff, tenants and relatives) was sought later, after MREC review had been granted. Feedback from the committee led to some amendments to the

proposals, which were then resubmitted. Faculty positive review was then given, the proposals submitted to the University Ethics Committee, and final positive review given with no further changes required.

4. Project Notification with NHS Trusts and Honorary Contracts..

As part of the Research Governance Framework outlined earlier in this paper, research needs to be registered with all Trusts within which it is carried out and researchers who carry out work within an NHS Trust, but are not employed by that Trust, should apply for an Honorary Contract (sometimes known as a License to Practice). Project registration is usually a matter of filling in a simple form, although some Trusts did ask for details of the number of hours required of each member of their staff who would be interviewed as part of the project. There is no commonly recognised honorary contract, although there are plans for such arrangements to be implemented in some regions. This meant that, for the very sheltered housing study, it was necessary to apply for honorary contracts from at least one, and often several, Trust(s) in each of the six areas in which the study was being carried out. Because this advice is relatively new and has not yet been formally implemented, some Trusts require honorary contracts to be sought by researchers while others don't. Likewise, for those Trusts that do make such a requirement there is considerable variation in the application processes in place. In the case of the current project, some Trusts merely wanted a single form to be completed, while others required occupational health checks, professional references and police checks to be carried out before issuing contracts. This can be a very time consuming process, both in terms of the paperwork involved and the time that application processes in general, and Criminal Records Bureau checks in particular, can take.

A number of key points emerge from this and other experiences of the ethics approval application process:

- Seek out as much information and advice as possible well in advance from other researchers, LREC administrators, etc;

- Include a realistic amount of time for ethical applications in your research plan, including amendments and resubmissions. Most committees will ask you to make some changes, and you can't start your research without their positive review;
- Ensure that research funders and commissioners are briefed early on about the necessity of the ethical applications process, and the likely implications in terms of amendments and resubmission. Housing Associations and other funders may have their own business priorities which have caused them to commission the research. They may also be expecting a quick turnaround in terms of delivering the final project so it is important that they are aware of the research governance regime and how it will affect the project timeframe. This is particularly an issue with smaller associations or local authorities which do not have a specific professional research function.
- If possible avoid applying for review by two organizations at the same time (e.g. LREC and university). This can lead to a situation where each is asking for different changes to be made and can result in a never-ending cycle of amendments and resubmissions. Other organisations will generally view NHS REC approval as a guarantee of ethical quality and will be less likely to ask for amendments to be made;
- Be philosophical and maintain your sense of humour. Remember that the ethical review process is necessary to protect both participants and researchers.

Implications for Housing Research

The Research Governance Framework has both short and long term implications for housing research. In the short term, more and more researchers will find themselves dealing with the kind of processes outlined in the case study especially when the framework is extended from the NHS to include all the responsibilities of social services authorities. This has clear time and cost implications since a whole new set of procedures may need to be allowed for. This may be

particularly problematic for two types of research. First, small scale pieces of applied housing research may become uneconomic if subjected to the requirements of the Framework especially when the funder is a housing organisation requiring quick feedback from the evaluators. Second, qualitative researchers and especially those using action research methodologies may find themselves 'on the defensive' in terms of the methodological assumptions underpinning both ethics forms and subsequent feedback from ethics committee. However, it is important not to get carried away with such a negative perspective. There is a strong qualitative research tradition in the NHS and Social Services and hence a developing and healthy debate about how to make the governance Framework work well across all methodologies. Of equal importance, common training is being developed for all members of NHS Ethics Committees and increasingly there is a recognition that their role should not involve interfering with the details of the proposed methodologies in specific projects.

The Research Governance Framework of the Department of Health also has some much longer term implications for housing research. First, it poses the question to Government of the logic of such detailed safeguards in health and social services research but their absence in other areas such as education and housing. The illogic of this is most clearly exposed by research on sheltered housing and residential care/nursing homes. Wardens and other support staff will not be covered by the Framework but residential and nursing home care staff would be. The tenants of sheltered housing will not be covered unless this is very sheltered housing (extra care) and the tenants are having their care funded through the local authority. Second, the DH Framework is forcing universities to review their ethics arrangements. Do they have an ethics committee? If yes, are its protocols and procedures clear enough and wide ranging enough? The outcome is likely to be a growing expectation that all human subject research based in universities is open to such scrutiny.

Conclusion

The likely impact of the DH Research Governance

Framework will be seen as at best a mixed blessing by most housing researchers. More delay and more bureaucracy seems bound to be the expectation of many. This leaves us to conclude with two brief observations. First, it is going to happen and so learning how to make it work is well worth the effort. Second, housing researchers do need to ask themselves if they have always given adequate time and thought to the protection of the rights of their research respondents.

Notes

1. Very sheltered housing is more generally referred to as 'extra care' housing. Broadly it is specialist housing with on site care provision
2. The study is the result of a collaboration between Housing 21 and Dementia Voice and is part-funded by a Housing Corporation Innovation & Good Practice Grant

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