

Research Standards, Principles of Ethical Research Practice and Summary of Key Responsibilities

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(Adults)**

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Research standards

1. All research must have a sound aim and demonstrate a clear link to strategy, policy, practice or developing new knowledge.
2. The quality of design, implementation and analysis of research must be reviewed independently through the Research Governance Lead to ensure it meets ethical standards, achieves a high level of rigour and is potentially beneficial to the service user, and / or the organisation, and/or likely to generate useful new knowledge.
3. All studies must have appropriate arrangements for obtaining informed consent from research participants and all those involved in research must be aware of their legal and ethical duties in this respect. This must include a standard statement that any complaints from research participants should be made to the Customer Liaison Manager and include the name of the social services manager to contact in the case of participant adverse events or the client being upset as a result of the research.
4. Attention must be given to systems for ensuring confidentiality of personal information and to the security of these systems.
5. Participants or their representatives should be involved wherever appropriate in the design, conduct, analysis and reporting of research.
6. Researchers should respect the diversity of human culture and conditions and take full account of ethnicity, gender, disability, age, economic status and sexual orientation in the research design, undertaking and reporting.
7. Some research might involve an element of risk to those participating in it. Risk must always be kept to a minimum, be identified explicitly and explained clearly in the research application to the South West London Research Governance Consortium (SWLRGC).
8. It is essential that existing sources of evidence, especially literature searches / systematic reviews, be considered carefully prior to undertaking research. Research or consultation which duplicates other work unnecessarily or which is not of sufficient quality to contribute something useful to existing knowledge is in itself unethical.
9. Data collected in the course of research must be retained for an appropriate period to allow further analysis by the original or other research teams, and to support monitoring of good research practice by regulatory and other authorities.
10. There should be free access to information both on the research being conducted and on the findings of the research, once these have been subjected to appropriate review. This information must be presented in a format understandable to the public. Reports need to be clear and take language and other needs into account.
11. All those pursuing social care research must open their work to critical review through the accepted academic and professional channels.

Principles of ethical research practice

Researchers engaging in research within or about the London Borough of Richmond's Adult or Housing Services must ensure that the aim, design and framework of the study meet the following ethical principles:

- 1. Consider carefully the possible consequences of the study for human beings.**

In planning all phases of social enquiry from design to presentation of findings the social researcher should be sensitive to the possible consequences of their work and should, as far as possible, guard against predictably harmful effects.

All information, however it is collected, can be misinterpreted. Social researchers will not be in a position to prevent action based on their findings. However, they should attempt to anticipate likely misinterpretations and counteract them when they occur.

- 2. Conduct research with objectivity, integrity and impartiality.**

Whilst research can never be entirely unbiased (due to the researcher's own value bias or a range of other factors imposed for example by the commissioning process) social researchers should attempt to uphold their professional integrity without fear or favour. They should not engage or collude in selecting methods designed to produce misleading results, or misrepresent findings by commission or omission.

They should clarify requirements in advance with the employer or funder.

When considering alternative methods and procedures for addressing particular inquiries they should provide a fair assessment of the individual pros and cons of the different methods and procedures.

Researchers should not accept contractual conditions that are dependent upon a particular outcome from a proposed inquiry.

One of the most difficult responsibilities researchers have is alerting the potential users of their data to the limits of their reliability. Caution should be taken to neither overstate nor understate the validity or the degree to which the data can be generalised.

- 3. Ensure that the physical, social and psychological well being of participants is not adversely affected by the research.**

Consent from the subjects does not clear the researcher from a duty to protect the subject as far as possible against any potentially harmful effects of participating. The researcher should try to minimise disturbance both to subjects themselves and to the subjects' relationship with their environment. Social researchers should help subjects protect their own interests by giving them prior information about the outcomes of participating.

Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, disability or illness, social status and powerlessness. Where the subjects of research are unable to participate

directly, proxies may need to be used in order to gather data. Care should be taken not to infringe the “private space” of the subject or to disturb the relationship between subject and proxy. Where indications exist or emerge that the subject would object to certain information being disclosed, such information should not be sought by proxy.

4. To seek the informed consent of participants.

Inquiries should be based as far as possible on the freely given informed consent of subjects. Subjects should be made aware of their right to refuse at any stage for whatever reason and to withdraw any data they have given. Information that would be likely to affect a subject’s willingness to participate should not be deliberately withheld, as this would prevent the subject protecting his or her own interests.

Informed consent involves providing an explanation of the nature and purpose of the research, the role of the participant, any possible harm or discomfort they might experience and the degree of anonymity and confidentiality. In the case of children or adults who may have difficulties in understanding or communication, consent should be sought from those who have the legal authority to give it such as parents and guardians.

In cases where the subjects are not approached for consent because access has been granted to records or data by their custodian the researcher should still consider the likely reactions, sensitivities and interest of the subjects concerned.

When informed consent conflicts with methodological requirements and there are strong reasons for not seeking it in advance consideration should be given to informing participants after the research has been completed.

5. Respect the privacy of individuals and maintain confidentiality of records and prevent disclosure of identity.

Researchers should ask for and record only personal information that is necessary for the study to achieve its purpose.

The identities and records of co-operating subjects should be kept confidential whether or not confidentiality has been explicitly promised. Individuals should not be identified either in the analysis or presentation of results without their specific and informed approval. Whenever possible anonymity should be preserved by breaking the link between the data and identifiable individuals - perhaps by using a system of codes. The identity and research records of those participating in the research should be kept in a secure manner and disclosed only to authorised personnel.

Wherever there is reasonable cause to suspect that a person is suffering or is likely to suffer significant harm as a result of the research it is the duty of the researcher to inform the officer appointed for participant welfare and / or the Research Governance Lead (RGL).

If within the research project it was considered that a breach of a participant’s confidentiality was required by law under Part IV of the Data Protection Act 1998 exceptions, this will not be done until it has been raised & agreed with the SWLRGC and the RGL.

6. Subject participants should be treated with equity and not discriminated against.

The design of the study should not discriminate against research workers or subjects on the basis of age, gender, ethnicity, religion, culture, disability or economic disadvantage. Participation in the study in either capacity should be on the basis of equal opportunity.

Richmond's adult and housing service is committed to user involvement and empowerment. Service users should be involved where appropriate to ensure that the research is relevant to their concerns and empowers them in relation to health and social care objectives.

Research findings should appropriately reflect the ways people differ as mentioned above.

7. Methods and procedures that have been used to produce published data should be open to scrutiny & assessment.

Social researchers may be given information that by law they are required to keep confidential. Methods and procedures that have been used to produce published data and findings should not, however, be kept confidential. They should be open to scrutiny and assessment and possible validation from colleagues and fellow researchers.

When working in partnership with colleagues in other disciplines social researchers must make these ethical principles clear and take account of the ethical principles of the other agencies.

Department of Health Summary of key responsibilities

Chief Investigator, Investigators, other researchers	<ul style="list-style-type: none">• Developing proposals that are sound and ethical• Seeking NHS research ethics committee approval, and / or independent ethical review in social care.• Conducting research to the agreed protocol (or proposal), in accordance with legal requirements and guidance• Ensuring participants' welfare while in the study• Feeding back results of research to participants.
South West London Research Governance Consortium (SWLRGC)	<ul style="list-style-type: none">• Providing an independent expert opinion on whether the proposed research is ethical, of value, methodologically sound and respects the dignity, rights, safety and well being of participants.
Sponsor	<ul style="list-style-type: none">• Taking overall responsibility for confirming that everything is ready for the research to begin, including:• Putting and keeping in place arrangements for initiation and management and funding of the study• Satisfying itself the research protocol, research team and research environment have passed appropriate quality assurance• Satisfying itself the study has ethical approval before it begins• Satisfying itself that access arrangements to respondents and/or their data are in place• Satisfying itself that arrangements will be kept in place for monitoring and reporting on the research, including prompt reporting of suspected serious adverse incidents• Ensuring the research complies with the law.
Main funder	<ul style="list-style-type: none">• Assessing the quality of the research as proposed• Establishing the value for money of the research as proposed• Assessing the quality of the research environment in which the research will be undertaken, and the experience and expertise of the chief investigator, principal investigator(s) and other key researchers involved• Requiring that a sponsor take on responsibility before the research begins.

Employing organisation	<ul style="list-style-type: none"> • Promoting a quality research culture • Ensuring researchers understand and discharge their responsibilities • Ensuring the research is properly designed, and that it is well managed, monitored and reported, as agreed with the sponsor • Taking action if misconduct or fraud is suspected.
Care organisation/ Responsible care professional	<ul style="list-style-type: none"> • Ensuring that research using their service users, carers or staff meets the standards set out in the Research Governance Framework (drawing on the ethical review and sponsor) • Ensuring there is ethical approval for all research for which they have a duty of care • Retaining responsibility for research participants' care.

Note 1:

The Funder, Sponsor, Employing Organisation and Care Organisation will often all be Richmond adult or housing services if the research has been commissioned as an in-house piece of work. In this case the person fulfilling the sponsors role will usually be a social services manager. If the study is part of academic work the University or College will be the Organisation and a named tutor the sponsor.

Note 2:

A more detailed explanation of responsibilities can be found in the Research Governance Framework for Health and Social Care (Second Edition 2005)