

Name & email supervisor(s):

Professor Geraldine Leydon

Length and dates of internship:

Funding will be based on 35 hours paid work per week, a total of 140 hours per placement.

4-week period between Monday 3rd June – Friday 27th September. (We will consider requests for this to be worked over a longer period on a part time basis)

Host department:

Primary Care, Population Sciences and Medical Education, University of Southampton

How will the internship be conducted:

- In person at the university
- Virtual/ from home
- Both are possible, depending on preference of student.

Title internship project:

Qualitative Data Sharing and Preservation for primary care research (Q-DaPs)

Summary of the internship project: *(max 250 words, can include hyperlinks to further information)*

Q-DaPS is funded by the School for Primary Care Research, the team comprises a group of primary care researchers, who work predominantly with qualitative data. The project is jointly led by Professor Fiona Stevenson (UCL) and Professor Geraldine Leydon (Southampton), with Dr Barbara Caddick (Bristol) as lead co-investigator and Dr Karen Lloyd (UCL) as Senior Research Associate. The wider team includes colleagues from the University of Oxford, Keele University, University of Southampton, University of Exeter, University of Bristol, and Aston University, as well as two public collaborators.

This internship will be supervised by Professor Leydon at Southampton University and this will involve working with the QDaPS team.

Background

Researchers may collect different types of data to increase understanding of issues in relation to primary healthcare. Data may include audio or video recordings of interviews, focus groups (group discussions), and consultations between professionals and patients / service users, as well as written data, such as notes about research. These types of data are referred to as qualitative data. There is a growing mandate amongst funders and journals for this type of research data to be retained and made available for others to reuse. Qualitative data collection is resource and time-intensive and can over burden already stretched primary healthcare sites (such as general practice). Secondary analysis of existing data can make good use of public money and maximise

the impact of research participants' contributions as well as removing the burden of recruiting or collecting new data through healthcare providers.

Sharing and re-use of qualitative primary care data remains controversial, with justified concerns about consent, de-identification and confidentiality, trust and data security, increased workloads, and the challenges of conducting secondary analysis.

Project aim

To design and develop with the primary care research community, a prototype repository within a secure, cloud-based data storage space that addresses the problem of archiving, whilst facilitating sharing and re-use of sensitive qualitative data.

What are we doing?

The Q-DaPS project involves:

- a qualitative interview/focus group study to explore key stakeholders' views on qualitative data sharing and re-use in health and social care research.
- a systematic scoping review of literature.
- work with a commercial provider to develop a novel prototype to facilitate safe storage and sharing of qualitative health and social care research data.
- an evaluation of the prototype repository.
- work with patient and public contributors throughout the project.
- stakeholder development and network building.
- Identification of areas where future work is needed.

Current project progress (February 2024)

Systematic scoping review of academic literature is underway.

Stakeholder study of 24 interviews with researchers and professionals with a responsibility for data management have been undertaken. Three focus groups with 12 previous participants in research have been carried out.

Prototype repository and integrated Trusted Research Environment has been built and handed over to the team for user testing and evaluation.

Student project

You will be supported by Professor Leydon with input from the wider Q-DaPS team and will be able to contribute to several areas of research:

- Review of policies and guidelines for research data archives; retention and sharing of primary care research data.
- Development of resources and guidance for retention, storage, and re-use of primary care health research data.
- Evaluation of repository and user guides to facilitate re-use and secondary analysis of qualitative data amongst primary care researchers.
- Analysis of qualitative stakeholder study (using transcripts)
- Public engagement work – assisting with designing accessible information about the project for different audiences (primary care researchers, primary care data custodians, patients and the public)

Learning objectives:

A range of transferable research skills can be developed through this internship:

- Understanding of primary health care research and the different disciplines and methods that are used to inform work in this field.
- Understanding of how research project and teams' function (particularly in collaboration across institutions).
- Learning about how research teams work with external commercial companies.
- An understanding of the complexities and debates that surround the retention and reuse of qualitative datasets from primary care research.
- Experience of PPI work
- Understanding how academic work is translated to make it accessible to different audiences.
- Gaining an understanding of the wider issues of the complexities of managing sensitive data to keep it secure (transferable to other contexts such as NHS data).
- An understanding of qualitative research and analysis (including ethics and consent).
- An understanding of regulation and wider issues relating to the use of sensitive health data (data governance, ethical concerns)
- Understanding how publication process works with opportunity to be named author on a research paper.

Any further information:

This internship is open to a student from any degree course, it might be particularly interesting to those studying humanities, social sciences, or data management (archives, library, oral history collections) with an interest in health. This internship will provide an overview and introduction to the type of research that takes place in the field of primary health care.