
Plan Overview

A Data Management Plan created using DMPonline

Title: Focus Group for NIHR Grant Application

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Affiliation: University of Manchester

Template: University of Manchester Generic Template

Project abstract:

This is not a research project, but a focus group for patients with osteoarthritis and their caregivers (PPI). We will involve up to 6 individuals in the focus group. The aim of the meeting will be to discuss their opinions on research in this field. We will particularly concentrate on a grant application we are in the process of submitting to NIHR for a study using regenerative medicine to treat osteoarthritis.

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Focus Group for NIHR Grant Application

Manchester Data Management Outline

1. Is this project already funded?

- Yes

Will you be applying for funding from any of the following sources? If your funder isn't listed, please enter in the free text box provided.

The Research Design Service (North West - NIHR) have agreed to give us £300 to carry out the focus group.

3. Is The University of Manchester the lead institution for this project?

- Yes - only institution involved

4. What data will you use in this project (please select all that apply)?

- Acquire new data

5. Where will the data be stored and backed-up during the project lifetime?

- University of Manchester Research Data Storage Service (Isilon)

6. If you will be using Research Data Storage, how much storage will you require?

- < 1 TB

7. If you have a contractual agreement with a 3rd party data provider will any of the data associated with this project be sourced from, processed or stored outside of the institutions and groups stated on your agreement?

- Not applicable

8. How long do you intend to keep your data for after the end of your project (in years)?

- 5 - 10 years

The information gathered from this meeting will be kept for 5 years so as to inform future grant applications.

Questions about personal information

Personal information or personal data, the two terms are often used interchangeably, relates to identifiable living individuals. Special category personal data is more sensitive information such as medical records, ethnic background, religious beliefs, political opinions, sexual orientation and criminal convictions or offences information. If you are not using personal data then you can skip the rest of this section.

Please note that in line with [data protection law](#) (the General Data Protection Regulation and Data Protection Act 2018), personal information should only be stored in an identifiable form for as long as is necessary for the project; it should be pseudonymised (partially de-identified) and/or anonymised (completely de-identified) as soon as practically possible. You must obtain the appropriate [ethical approval](#) in order to use identifiable personal data.

9. What type of person identifying information will you be processing (please select all that apply)?

- No sensitive or personal data

We will not be recording any sensitive or personal data, only opinions and thoughts collectively discussed during the focus group on future directions of our research. The data will be summarised during the event by a scribe (member of the research team) and approved by all present. Quotes may be used in the write-up, but no identifiable information such as names will be referenced.

10. Please provide details of how you plan to store, protect and ensure confidentiality of the participants' information as stated in the question above.

No identifiable information will be collected for this focus group. It will therefore not be possible to identify the individuals involved from the data collected.

11. If you are storing personal information will you need to keep it beyond the end of the project?

- Not applicable

12. Sharing person identifiable information can present risks to participants' privacy, researchers and the institution. Will the participants' information (personal and/or sensitive) be shared with or accessed by anyone outside of the University of Manchester? This includes using 3rd party service providers such as cloud storage providers or survey platforms.

- No

13. If you will be sharing personal information outside of the University of Manchester will the individual or organisation you are sharing with be outside the EEA?

- Not applicable

14. Are you planning to use the personal information for future purposes such as research?

- No

No personal information will be recorded.

15. Who will act as the data custodian or information asset owner for this study?

Leela Biant

16. Please provide the date on which this plan was last reviewed (dd/mm/yyyy).

08/02/2019

Project details

What is the purpose of your research project?

We wish to invite patients with end-stage osteoarthritis of the knee and/or patients who have undergone a total knee replacement within the last year and/or their family members/friends/caregivers to participate in a discussion group. The aim will be to gather information on the opinions of patients and their family members/friends/caregivers on regenerative treatments for knee osteoarthritis.

What policies and guidelines on data management, data sharing, and data security are relevant to your research project?

The General Data Protection Regulation (GDPR) will be adhered to, as will policies of the research group, department, and institution including The University of Manchester Records Management Policy, The University of Manchester Data Protection Policy and the University of Manchester IT Policies and Guidelines.

Responsibilities and Resources

Who will be responsible for data management?

Professor Leela Biant and Dr Gwenllian Tawy

What resources will you require to deliver your plan?

Access to the University of Manchester Research Data Storage service will be required to deliver this plan. There will be no storage costs associated with this study, nor will research staff be required to undergo any relevant training for this investigation.

Data Collection

What data will you collect or create?

During this meeting, a member of the research team will describe an intended study on regenerative medicine in knee osteoarthritis to the patients. As patients who would be/would have been eligible for the study, the group will be encouraged to discuss the acceptability and feasibility of the study from their perspective. The group will explore ways to overcome any potential issues associated with the current protocol. The information gathered will be used by the patients and researchers to alter and improve the protocol, prior to it being submitted as part of a grant application. This provides patients with a means of directly shaping the study with the researchers.

Summarised notes of the discussion had with the participants. These will be typed and edited by a member of the research team with the participants during the focus group. The notes will not identify any individuals.

How will the data be collected or created?

During the focus group, a member of the research team will write summaries of the discussions in a Word document. Some quotes may be used, but no names or identifiable information will be used against these quotes. All individuals will read and edit the summarised document together to ensure that all agree with the content.

Documentation and Metadata

What documentation and metadata will accompany the data?

None will be needed. The document will be self-explanatory.

Ethics and Legal Compliance

How will you manage any ethical issues?

According to INVOLVE, the national advisory board that supports patient and public involvement in the NHS, ethical approval is not needed for focus groups of this sort, as long as the findings are not published as research. For this reason we will not seek ethical approval.

Participants will be compensated for their time (£10) and reimbursed for travel (£10) to and from the hospital for the meeting. This amount of payment given is consistent with INVOLVE guidance and has been approved by the funders. To overcome potential coercion into the focus group, the amount of money which will be gifted to individuals will not be disclosed on the advertisement.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

In the unlikely even that this focus group will lead to new IP, The University of Manchester own the copyright and IPR of any new and existing data.

Storage and backup

How will the data be stored and backed up?

The data recorded during the focus group will be written into a Word document stored and backed up to the University of Manchester Research Data Storage system. This system is backed up every day and is secure.

How will you manage access and security?

Only the PI (Leela Biant) and researcher (Gwenllian Tawy) will be given access to the data. This restriction will be put in place by the IT team at the University of Manchester who are responsible for granting access to staff members using the University of Manchester Research Data Storage system. The PI will inform the IT team who can access the data. All those with access will be required to enter a

password to access the data.

The data will not be shared with anyone outside the University of Manchester.

Selection and Preservation

Which data should be retained, shared, and/or preserved?

The document created during the focus group will be kept for 5 years and used to inform future grant applications.

What is the long-term preservation plan for the dataset?

The document will be destroyed after 5 years.

Data Sharing

How will you share the data?

The information gathered during this focus group will be summarised in a document and used to inform future grant applications. The information will not be published as research.

Are any restrictions on data sharing required?

No, as no identifiable information will be recorded.