Lay Advice on Diabetes & Endocrine Research (LADDER)
Academic Directorate of Diabetes & Endocrinology

Frequently Asked PPI Questions

This document has been prepared by Patient Lay Advisory Panel within the Academic Directorate of Diabetes & Endocrinology (LADDER) at Sheffield Teaching Hospital NHS Foundation Trust. The document is designed to highlight key questions researchers and patient panel members may ask each other, when discussing research.

The document is in two sections and in each section the questions are broken down into the different phases of research. The sections are as follows:

SECTION 1 - Standard PPI questions researchers can ask a public involvement panel:

SECTION 2 Standard PPI questions a public involvement panel can ask a researcher:

We hope you find this document useful and we thank Sheffield Hospitals Charity for their support with all Patient and Public Research initiatives at our hospital.

Sheffield Hospitals Charity

If you have any comments on this document we would love to hear from you, please email getinvolved@sth.nhs.uk

If you wish to find out more about our Patient and Public Research initiatives please visit

http://www.sheffieldclinicalresearch.org/for-patients-public/

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SECTION 1 - Standard PPI questions researchers can ask a public involvement panel:

Pre Funding

1. **Identify Clinically Related Problem**
    - Do you think patients perceive this to be a problem?
    - Do you think this problem is worth investigating?
    - Is the proposed idea seen as worthwhile to patients?

2. **Establish the Research Question**
    - Is the research question clear to patients?
    - Do you think that the project is worthwhile?
    - Do you think the project will benefit patients?
    - Do you support the research in principle?

3. **Research Design**
    - Is the reason for doing the study clear?
    - Is the purpose of the study understandable?
    - Did you understand what the project was about from the Lay Summary alone without looking up terminology?
    - Do you think Lay members of the grant review panel would understand the lay summary and consider it a 'plain English' description?
    - Do you think patients will agree to participate?
    - Would high risk patients want to participate?
    - Is the patient journey clearly set out?
    - Is the patient journey appropriate?
    - Is the frequency of visits acceptable?
    - Is the interval between proposed study visits appropriate?
    - Are the requirements of the study acceptable to the participants?
    - Is the researcher asking too much of the patient at each study visit?
    - Are the proposed visits too long/intensive?
    - What could be done to make the project more acceptable to patients/participants?
    - Do you have concerns about the tolerability of the procedures?
    - Do you think the chance of receiving placebo would put people off participating in the study?
    - Should patients be offered longer term use of the medication being trialled, if it proves effective?
    - Do you think patient benefit is enough to motivate patients to participate or should another incentive be offered? E.g. compensation for time, reimbursement of travel expenses
    - Do you have any concerns over the use of the proposed medications?
    - What is a patient's view of taking an unlicensed drug?
    - Do you think anything has been missed?

- Can you think of ways to improve the research?
- What will help you understand the project better?
- Do you have any suggestions to enhance recruitment and retention to the study?
- If funded, would the panel/individual patient agree to act as part of the project steering committee?

4. **Submit Proposal**
    - Are any of the panel members interested in being a co-applicant?
    - Will the panel be able to review a final version before submission?

<u>Post Funding</u>

5. **Approval and Ethics**
    - Are any of the panel members interested in writing or reviewing the lay summary?
    - Are any of the panel members interested in writing or reviewing the patient information sheets?
    - What terminologies should be used/avoided in participant information sheets/consent form?
    - Do you understand what the project is about from the participant information sheets/consent form?
    - Do you understand from the participant information sheets/consent form what the patient journey is?
    - Would you consent to take part in the study if asked or do you have any outstanding questions after reading the participant information sheets/consent form?
6. **Deliver and Complete the Study**
    - Can you suggest contact avenues for getting more subject participants?
    - Are any of the panel members interested in being part of the project steering group?
    - Are any of the panel members interested in representing service users on the Trial Management group?
    - Will the panel be willing to receive reports on progress at key stages?

7. **Dissemination of Research Findings**
    - Can you suggest ways of sharing the results/findings with the general and target population?
    - Are Panel members interested in participating in dissemination events?
    - Will the Panel be willing to review dissemination materials from a patient viewpoint?

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SECTION 2 Standard PPI questions a public involvement panel can ask a researcher:

Pre Funding

1. Research Design

- What is the benefit to patients of participating?
- What is expected of the participant during the study?
- What is the participant journey and is it appropriate (are the frequency of visits and procedures at each visit acceptable)?
- Will the study drug/device be made available to participants when the study finishes?
- Are the proposals for recruitment realistic?
- Is the proposed duration of the study adequate to address the research question?
- Are there sufficient research arms to test all the variables of interest to patients?
- Who is the target audience for the project (participants)?
- What are the inclusion and exclusion criteria?
- Will patients agree to participate?
- Will high risk patients want to participate?
- Will the chance of receiving placebo put people off participating in the study?
- Should patients be offered longer term use of the medication being trialled, if it proves effective?
- Is the patient benefit enough to motivate patients to participate or should another incentive be offered? E.g. compensation for time, reimbursement of travel expenses
- Are there any concerns over the use of the proposed medications?
- What is a patient's view of taking an unlicensed drug?
- Do you think anything has been missed?

Post Funding

2. Deliver and Complete the Study

- What planning is being done if the study fails to recruit?
- What, if any, support or interventions from the Panel will help successful delivery?

3. Dissemination of Research Findings

- How will the study results be shared with the participants and general /target population?
- Can you suggest ways to disseminate results from this study?
- Can you understand the patient focused dissemination materials
- What, if any, help and support from Panel members might be needed in the dissemination phase?