NHS SCOTLAND

NHS RESEARCH SCOTLAND

PPI in basic science in diabetes

March 2024

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and

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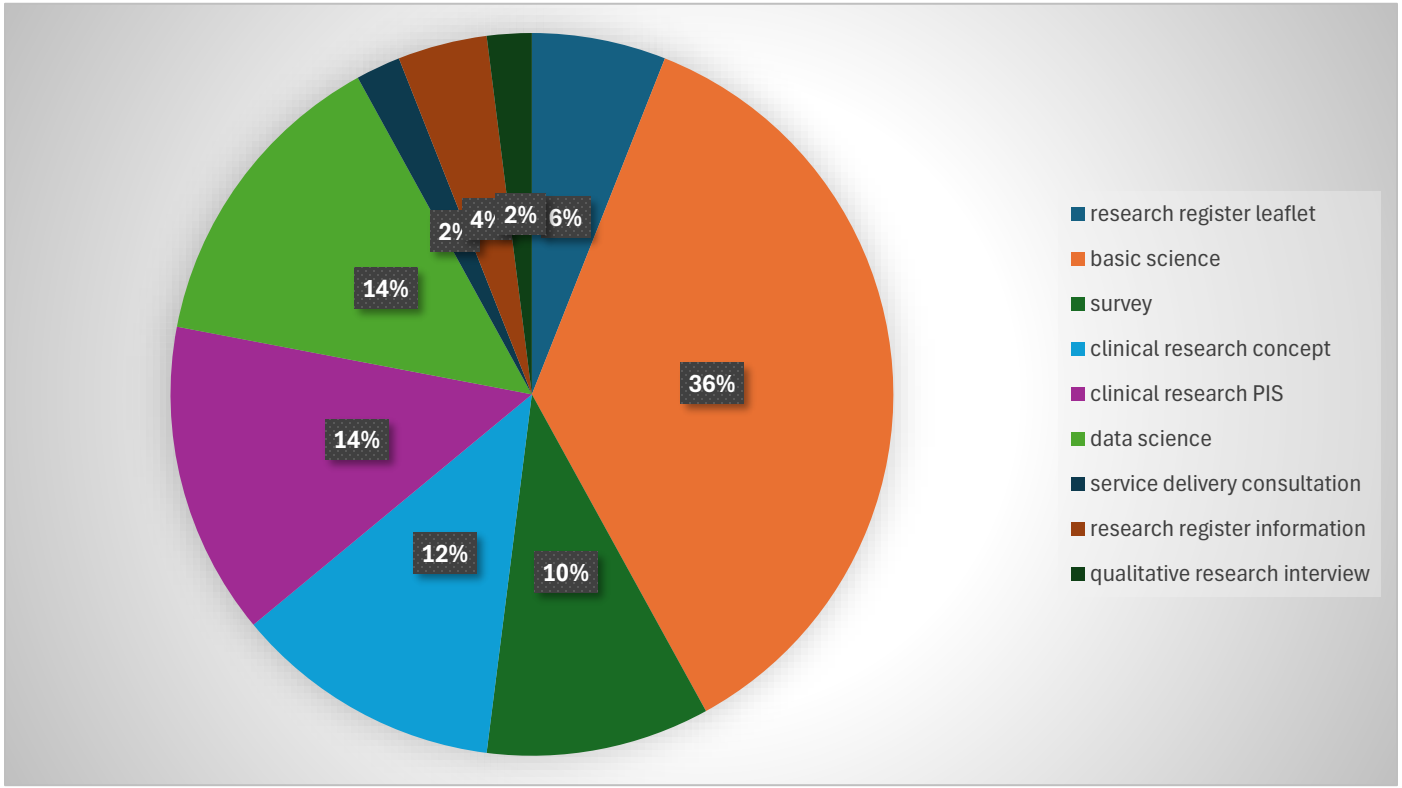
18 out of 50 of PPI task requests were for basic science projects



Who requires PPI for basic science research?

- Those working in the NHS and Universities
- Experienced members of staff for programme grants and project grants
- Early career researchers for fellowship applications
- Clinical research fellows for project grants or training applications

Basic science/ lab-based research in diabetes covers a variety of topic areas

- **Early-stage lab science for new treatments for type 2 diabetes, obesity and metabolic disorders**
- **Large funding calls from the “Type 1 Diabetes Grand Challenge” (JDRF/DUK)**
- **Novel insulins**
- **How diabetes develops / Factors contributing to diabetes progression**
- **Genetics and diabetes**
- **Brain responses to glucose**

What are the barriers to navigate from the researcher side?

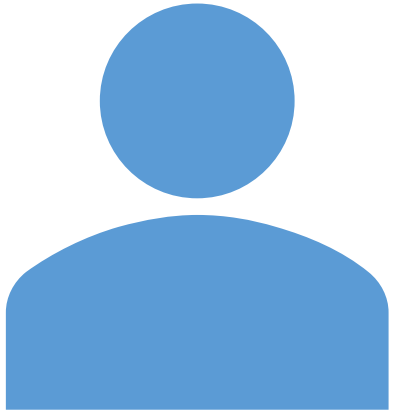
- Unsure how to find patients as not likely to encounter day to day at work
- Never spoken to patients before, may struggle to explain in lay language
- General worries about communication (e.g. being asked health related questions)
- Belief that an interaction with patients would not add much
- Low expectation of having a meaningful scientific conversation
- Unwilling to engage with patients to contribute to lab-based study design
- The time taken to obtain PPI feedback for each funding application

What are the possible positive outcomes from the researcher side?

"Diverse opinions can help to get perspective on the bigger picture."

"I have always found the feedback on the lay section extremely useful, not just to help communicate better what we are trying to do but in helping shape concepts and justify research aims."

"PPI made me think about how patients will truly benefit from any discovery, and what the timescale for this would realistically be."



Researchers should

Prepare

Spend time to write a lay summary with good grammar and few typos.

PPI group prefer to receive a set of specific questions to focus their attention and provide guidance.

Allow time

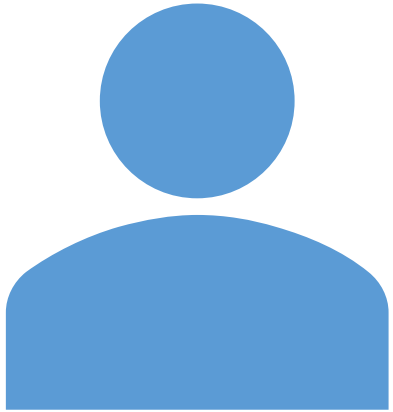
Questions and documents sent with plenty of time for review

Implement

Collate responses (may be required to evidence)

Consider responses and what you will change in the application

Helpful if researchers can write a short, personal note of thanks and explain what in particular they might have taken forward or changed as a result of seeking PPI feedback



PPI contributors will

- Review to the best of their ability and time available.
- Not provide professional level critical comment.
- Give useful insight of the research from the patient point of view.
- Indicate whether you have managed to convey the importance of your research question to a lay audience.

Where should basic science researchers engage further with PPI (at the research design stage)?

<u>ROUTINELY DOING</u>

Review or develop plain English summaries

<u>COULD DO MORE</u>

Inform research priorities and identify what is important for patients

Inform research questions & outcomes

Inform where PPI can be embedded into the project

Input into the funding application

Have a patient partner co-applicant on the funding application

<u>UNLIKELY TO BE APPROPRIATE</u>

Input into appropriate research methods

<u>NOT APPLICABLE</u>

Assist with recruitment and retention strategies

Review or develop questionnaires

Learning outcomes from PPI on basic science

Issue	Resolution
The lay summary is too scientific	PPI facilitator should intervene (ideally before this is sent out) Consider an interpretation/re-write Consider offering 2 versions (original and re-write) and ask which is better Too complex and response rate from PPI will be low/nil
Timeline given to respond is too short	2 weeks minimum
There is no clear relevance to diabetes patients or project relevant to a specific sub-set only	Engage with the relevant subset if possible
“Diabetes” is used without specifically stating type 1 or type 2	Understand the difference – one is autoimmune condition, the other is not
Questions may not be answered or may be answered literally	Consider using a videoconference to have a more interactive dialogue

Q&A with PPI panel member Jennifer Watson

1. How long has type 1 diabetes been a part of your life?
2. Why did you decide to get involved in PPI?
3. What happens when you get an email about a PPI task – what factors might influence what you do next?
4. What would put you off from responding to a PPI task?
5. After helping with a PPI task what follow up do you like to receive?
6. How do you think that PPI can help researchers?