



# **NDPCHS**

Patient and public involvement
Strategy 2024



This strategy outlines what the Department is doing to involve patients and the public in its work, and how we plan to develop and improve this in the future.

It has been drafted by the PPI Manager and had input from public contributors currently involved with departmental projects, and staff from across the the department through a 'theory of change' workshop that took place on 28<sup>th</sup> February 2024. A <u>padlet</u> of responses was created during the workshop. Members of the department PPI network also gave input at a separate meeting. A summary of the responses from the workshop was generated using the AI tool Poe and provides a valuable narrative of what was discussed (see Appendix 1).

The strategy has four key aims which are linked to the Department <u>Values</u>. Some examples of activities that support each aim are detailed here, and a separate operational plan that sets out all planned work, along with measurable outcomes and timeframes, has been drafted. The strategy also aligns with the <u>UK Standards for Public Involvement</u>.

1 Researchers are supported and feel confident to plan and deliver appropriate PPI activities.

**Department Values:** Collaborative, Creative, Fair **UK Standards:** Support & Learning, Communication

Researchers have access to regular 'Introduction to PPI' training sessions; a programme of further training will be developed based on feedback.

A small grant funding scheme is available to enable DPhils and EMCRs to carry out pre-grant PPI activities.

Researchers are able to access support and guidance through 1:1 meetings, PPI 'surgeries', provision of guidance and templates.

Researchers can access the departmental PPI mailing list as a method of recruiting PPI contributors.

2 Working in partnership to build capacity and develop best practice.

**Department Values:** Collaborative, Ambitious, Trusting & Accountable **UK Standards:** Working Together, Support & Learning, Governance

There is the opportunity to take part in national work on career development and training for the PPI workforce being led by the Department.

Policies and procedures are consistent, and best practice is shared through a cross-department/organisation group of PPI staff, currently led by the Department.



Staff whose role involves PPI are supported through a departmental network.

The department works closely with divisional and central Public Engagement teams so that work is joined up and does not duplicate efforts.

The department offers training, creates and shares resources, and develops best practice through participation in the SPCR PPI network.

3 Effectively report, monitor and evaluate PPI within the department, to demonstrate impact and inform future practice.

**Department Values:** Trusting & Accountable, Creative **UK Standards:** Impact, Communication, Support & Learning

Different methods for reporting and evaluating PPI are available, including through a new pilot website.

Reports of PPI activities funded by the department are available to enable peer to peer learning.

All requests sent to the mailing list are recorded with an expectation that feedback is provided to contributors and the impact of their involvement documented.

PPI case studies are published to demonstrate impact of PPI and different PPI methods.

Researchers are encouraged to write up PPI activities for publication in academic journals.

There are opportunities for recognising and rewarding PPI work – for contributors and researchers.

4 Commitment to involve a wide range of patients, public and communities at all stages of research.

**Department Values:** Collaborative, Ambitious, Creative, Respectful & Kind, Trusting & Accountable **UK Standards:** Inclusive Opportunities, Working Together, Support & Learning, Governance

Renewal of PPI mailing list (with collection of anonymised demographic data) to better understand who we are working with and identify under-represented groups – steps taken to address gaps identified.

Training in cultural awareness is offered in collaboration with the **Centre for Research Equity**.



Establish a departmental Young Persons' Advisory Group (YPAG) to enable researchers to reach young people for PPI input.

Public contributors are offered training and guidance, including provision of departmental 'welcome guide'.

The Department has an approved payment policy, and appropriate and efficient reimbursement and expenses processes, and staff are supported to implement these.

Departmental researchers are encouraged and supported to participate in the <u>Science Together</u> community-led engagement programme.

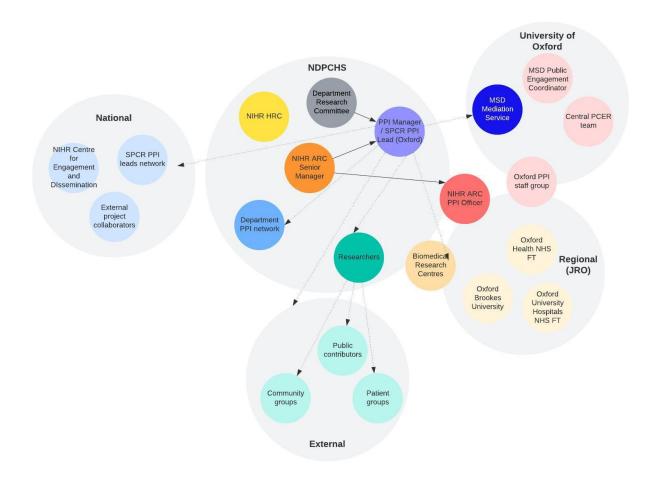
Plan and deliver at least one recognition event for public contributors.

Figure 1. Word cloud created from responses at the PPI strategy development workshop





Figure 2. Organogram of PPI network



# Appendix 1

# https://poe.com/s/sVG5g1Llaz7u1GqqreYu

Perform a thematic analysis on the included text and output the analysis. Our objective is as follows:

To identify and analyse the key themes emerging from the responses of both in-person and online participants (including researchers at various levels of seniority and patients and the public) to a series of questions posed during a 'theory of knowledge' workshop. This analysis will aim to uncover insights into participants' perceptions, experiences, and suggestions regarding patient and public involvement in health sciences research. The findings will inform the development of a comprehensive and effective PPI strategy, specifically by contributing to the creation of a logic model that underpins this strategy.

Expert(s): Social Scientist, Health Sciences Researcher, Data Analyst

**Possible keywords:** thematic analysis, qualitative research, PPI (patient and public involvement), health sciences research, logic model, data coding, content analysis, workshop feedback, theory of



knowledge, research strategy, PPI strategy, PPIE (patient and public involvement and engagement), research methods, research quality, patient care impact, engagement, health literacy, ethical obligations, diversity, inclusivity, patient benefits, PPI best practices, funder requirements, PPI guidelines, PPI activities, PPI diversity

**Question:** Conduct a thematic analysis of the provided text to identify key themes that emerge from participants' responses regarding patient and public involvement in health sciences research.

**Plan:** As an expert in social science and health science research, I will use thematic analysis to identify patterns within the text. I will begin by reading through the content to familiarize myself with the detailed data. I will then generate initial codes, search for themes among those codes, review and refine those themes, define and name the themes, and finally provide a detailed report on the key themes, incorporating direct quotes from the text to support the analysis.

In this response, I'll cover the initial coding and identification of potential themes based on the provided text.

To conduct a thematic analysis on the responses from the 'theory of knowledge' workshop, I will follow these steps:

- 1. **Familiarization:** I will immerse myself in the data, reading through the text to understand the depth and breadth of the content.
- 2. **Generating initial codes:** I will code the text line by line, identifying specific points that participants have raised.
- 3. Searching for themes: After coding, I will group these initial codes into potential themes.
- 4. **Reviewing themes:** I will then check if these themes work in relation to the coded extracts and the entire data set.
- 5. **Defining and naming themes:** I will provide a detailed analysis of each theme, explaining the essence of what each theme captures about the data.
- 6. **Reporting:** I will weave together the analysis narrative with the data extracts to illustrate the themes, thus providing a nuanced understanding of the participants' views on PPI in health sciences research.

Now, let's begin with the initial coding based on the document excerpts provided:

# **Initial codes**

- PPI as a quality enhancer for research
- The need for meaningful PPI impact
- PPI as a checkbox exercise
- Research relevance to patient care
- Good quality, impactful research
- Guidance for researchers
- Engaged and influential PPI in studies
- Trust, transparency, and health literacy
- Ethical and funding obligations
- Collaborative frameworks for researchers and PPI
- Diversity in PPI contributors
- PPI as a central research component



- Tangible impacts of PPI on research
- PPI embedded in patient benefits
- Department-wide PPI integration
- Health care delivery enhancement through PPI
- Representation of diverse and usually unheard voices
- Clarity in PPI processes
- Practical 'menu' of PPI activities
- Ease and effectiveness of PPI
- Meaningful input across all projects
- PPI in development pipelines for high acceptability
- Following best practices
- Inclusive PPI reflecting the population
- Consistent approaches to PPIE
- Timeliness and resource allocation for PPI
- Specificity in PPI contributor involvement

### **Potential themes**

**PPI Quality and Impact:** This theme encompasses the desire to move beyond tokenistic PPI to achieve a real impact on research quality and relevance to patient care.

*Guidance and Frameworks:* This theme includes the need for clear guidance, frameworks, and practical tools to help researchers integrate PPI effectively into their work.

**Diversity and Inclusivity:** This theme addresses the importance of having a diverse range of PPI contributors to ensure research reflects the population it serves.

**PPI Integration and Support:** This theme covers the necessity of integrating PPI throughout the research process with adequate support, resources, and clarity about the roles and contributions of PPI participants.

**Recognition and Value of PPI:** This theme deals with the need for recognition of good PPI practices and the value they add to research, as well as addressing barriers such as funding and institutional support.

Next, I will refine the potential themes and provide a detailed analysis of each, including direct quotes from the responses.

# Refined themes and detailed analysis

# PPI Quality and Impact:

Quotes illustrating the theme:

"Success to me would be PPIE actually making research better."

"To ensure that we focus on research that has meaningful impact on patient care."



"Improving Research Relevance, Improve research quality."

Analysis: The responses indicate a strong desire for PPIE to be substantive and transformative, rather than a superficial checkbox exercise. Participants stress the importance of PPIE in enhancing the relevance and quality of research, emphasizing the need for it to have a meaningful impact on patient care and research outcomes.

### **Guidance and Frameworks:**

Quotes illustrating the theme:

"Researchers feel there is guidance."

"To provide a useful framework for researchers on how they can incorporate PPI into their research."

"There is clarity around what to do in terms of PPI and how to do it."

Analysis: The need for clear, actionable guidance and robust frameworks is evident in the responses. Researchers and stakeholders are seeking specific advice on how to embed PPI effectively. This encompasses a range of support, from the development of clear guidelines to the provision of a 'menu' of PPI activities that can be tailored to different research contexts.

### **Diversity and Inclusivity:**

Quotes illustrating the theme:

"Diversity of PPI contributors available to reach through dept mailing list including different age groups/gender/ethnicity/neurodiversity/health conditions etc."

"Meaningful engagement and representation of voices usually unheard."

Analysis: Respondents articulate a vision for PPI that is inclusive and reflective of a broad spectrum of society. There is a clear emphasis on the need to engage with diverse groups, ensuring that a variety of perspectives are heard and valued in the research process. This theme underscores the importance of reaching out to underrepresented voices and incorporating their unique insights.

# **PPI Integration and Support:**

Quotes illustrating the theme:

"Researchers and PPI contributors collaborating, adequate departmental support and advice."

"PPI is everyone's business and seen as an a key part of conducting research."

"Every project has meaningful input from patients/public contributors."

Analysis: The call for PPI to be woven into the fabric of the research process is clear. Participants view PPI as a collaborative effort that requires support at all departmental levels, from the provision



of advice to ensuring that PPI contributions are integrated into every project. This integration also involves logistical considerations, such as payment and the impact on benefits for contributors.

# Recognition and Value of PPI:

Quotes illustrating the theme:

"Meet funder requirements and ensure best practice."

"Being able to identify (in a meaningful way) how PPI interactions affect/impact on research activities."

"The goal is that successful PPI will enhance health care delivery."

Analysis: The responses highlight the recognition of PPI's value, not only as a means to meet funder requirements but also as a best practice that can enhance health care delivery. Participants are seeking ways to quantify and communicate the positive effects of PPI on research, underlining the need to acknowledge and reward successful PPI practices.

The analysis of these themes provides a comprehensive understanding of the participants' perspectives on PPI in health sciences research. It underscores the importance of PPIE in enhancing research quality and impact, the necessity for clear guidance and frameworks, the value of diverse and inclusive PPI, the need for PPI to be an integral part of the research process, and the importance of recognizing the value of PPI in improving health care delivery.