

VOCAL

Landscape review of public involvement in non-clinical research



Appendix 2

“When we talk about public involvement, we mean all the ways in which the research community works together with people including patients, carers, advocates, service users, and members of the community. Excellent public involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes, as set out in the UK Standards for Public Involvement.”

The Shared Commitment to Public Involvement

**This work was commissioned by the
Medical Research Council**

VOCAL



**Medical
Research
Council**

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Introduction

Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research (February–September 2022), with a specific focus on non-clinical health and biomedical research.

This Appendix is a review of the external landscape and demonstrates that there is a developing community of practice for public involvement with non-clinical research.

There is clear evidence of people and patients being actively involved with the non-clinical research landscape including the UK, Ireland and Canada. This is seen through online discussion, and the existing literature including some emerging scoping reviews. In the UK, we are aware of research teams and organisations who are already successfully involving public partners with non-clinical research, and a host of established research teams/organisations who are starting out and grappling with how best to develop and deliver this work.

Public partners, researchers and involvement practitioners we spoke with seemed pleased that this review is taking place and are seeking a meeting place, opportunities to exchange ideas and develop practice. There is a desire for this involvement to be encouraged, to be open and inventive within clear guidance and support rather than fixed process driven model.

The following sections provide information from the landscape external to MRC about public involvement in non-clinical research.

Section 1 provides case studies with information sourced through interviews and desk-based research. Section 2 is a scoping review of examples of public involvement in non-clinical research across the research environment.

1. Case studies with relevance to MRC challenges

Case study A

Programme-level public involvement strategy in fundamental research focused on publicly contentious issues:

What makes us human? Public engagement and involvement with the Human Developmental Biology Initiative (HDBI).

Introduction and context

The HDBI is a Wellcome Trust funded research initiative, with close links to the Human Cell Atlas. Mostly UK based, it has four research themes split across seven institutions including the Babraham Institute, Francis Crick Institute, Gurdon Institute at the University of Cambridge, Wellcome-MRC Stem Cell Institute at the University of Cambridge, University of Newcastle, Oxford University, and University College London. The Wellcome Trust has committed £10m to fund the HDBI for 5 years (2019 – 2024) to create a step-change in fundamental knowledge about human development leading to improved health outcomes in fertility, birth conditions and regenerative medicine. This public engagement strategy received an additional £537K of funding for delivery across the UK, 2020–2024.

Human developmental biology research raises ethical, legal, social issues (ELSI) in terms of the research relying on the use of human embryo and fetal tissue, how this tissue is sourced, and how we use knowledge generated by the research in the future.

In 2020, Vocal was commissioned by the Wellcome Trust to work with the HDBI and develop a public engagement strategy and implementation plan (available on request). At this time, whilst all of the researchers we worked with were supportive of public engagement, and most could provide examples of communications/engagement activities that they had been involved with, very few examples centred on ELSI relating to human developmental biology, and none actively sought public insight or involvement. The researchers had enormous respect and gratitude for tissue donors, and demonstrated how seriously they took their responsibilities in working with this human tissue. Most important to all researchers interviewed was the need for maintained donation of tissue for research. However, with their work focusing on basic research, no HDBI researchers interviewed were able to describe value to their research that could be gained from insight from people and patients.

Public engagement in HDBI was being limited by the highly emotive nature of the research, both in terms of some of the focus areas e.g. miscarriage, fertility, and especially because the research uses human embryos and fetuses. For many HDBI researchers, there were barriers to engagement because there were risks of 'saying the wrong thing', and the anticipated fall out from this would be to degrade public trust with HDB research. This may have consequences on people's decision to donate embryos and fetuses for research purposes and – in the researchers' worst-case scenario – cause regressive changes to regulation.

1. Case studies with relevance to MRC challenges

What was the activity?

The HDBI public engagement stated vision is: 'HDBI research anticipates and responds to societal needs by systematically engaging with and reflecting on opinions, perspectives and priorities of patients, public and wider stakeholders'. The work is overseen by Dr Emma Rawlins (Academic Lead) and led by Naomi Clements-Brod (Programme Manager) at the Gurdon Institute, with a PE working group of practitioners representing the 7 institutions. Importantly, the focus of the strategy is on capacity development in order to: systematically address barriers that prevent the full potential of engagement; provide flexibility to respond to arising needs within research or policy, and secure a legacy of engagement beyond the funding period.

As such the public engagement strategy includes ongoing training and development for all HDBI researchers including ELSI training and seminars, horizon scanning and reflection days, training in having difficult conversations, and in working with the media.

At the core of the PE strategy is the Insights Group – a mixed experience group of people and professionals, including women and men who have experience of IVF services, or termination of pregnancy services. This Group is now established and a publication describing this process is in press (available on request).

The Insights Group has a broad remit within the HDBI including to:

- Support researchers' consideration of ELSI issues arising within the research, and future horizon scanning
- Improve communication of research, including working with researchers to create common language, and image bank, improve lay summaries
- Improve training for researchers including co-production/delivery of training and supporting researchers to have difficult conversations in a safe space.
- Improve public engagement design and delivery – e.g. deliver activity, feed into commissioning and co-design of a public dialogue informing policy
- Improve evaluation of public engagement.

The HDBI public engagement programme has been running for approximately 12 months and is making good progress. The Insights Group is established and at the time of writing have met on four occasions. There have been immediate impacts for researchers in considering how they present and talk about their work, including through language and images, and in understanding the needs, motivations and interests of the Insights Group in order for them to gain benefit and contribute confidently.

Importantly, the HDBI has a 0.8 FTE Programme Manager in post, a PE Steering Group to oversee the project, and a distributed network of delivery through experienced PEPs.

Emma Rawlins said: "I don't think that you can emphasise enough to the MRC that having a PE manager and professional PE people involved makes this work. The scientists are getting involved, but do not have the time to drive it forwards."

HDBI has an independent evaluator who worked with Vocal and HDBI from the outset. Vocal continues to mentor and support the PE Programme Lead.

1. Case studies with relevance to MRC challenges

How could this case study support the MRC?

Several research teams involved in the HDBI are also part-MRC funded, and Emma Rawlins, the Academic PE Lead, is an MRC Senior Fellow. There are Public Engagement and Communications Professionals within MRC Establishments e.g. Crick, who will be able to share their learning and experiences of being part of the HDBI engagement programme. This case study demonstrates an approach designed to overcome barriers around 'saying the wrong thing' in contentious issues, and in gaining public insight where its most valuable – not around basic research methodology – but in the surrounding context, arising questions, and future implications of this fundamental biology and its interface with society.

Considering how and why people should be involved across the research environment, rather than only within the research cycle, can be applied to other areas of challenge for the MRC including health data science, animal research, discovery science and experimental medicine.

The HDBI engagement strategy is a bold and innovative step and the HDBI senior leadership recognise both its potential and its challenges. The foundations are in place to take this forward successfully and there will be significant learning to share, both from reflective practice, and the formal evaluation.

Case study D: Investment in public involvement across relevant funding organisations

TABLE 1: Funding organisations investment and infrastructure for public involvement (PI)

Funder	Approximate research spend per year	Annual spend on PI (if known)	PI within research grants	Standalone funding for PI	PI staffing (central and across infrastructure)	Trends/ notable information
CRUK	£443m	No figure available as involvement costs are embedded throughout organisational budgets.	CRUK have a clear statement of intent. There is a question about involvement in all clinical research grant applications, but not for non-clinical. Funding is available for PPI across all grants.	No	CRUK has a central team of 6 staff who work in PPI (including public-facing comms specific to PPI). They have a national team of 15 research nurses who have PPI as part of their role. Each CRUK 'establishment' has a designated PPI Lead. This may be part of another role, or a sole focus on PPI.	They are increasing public involvement in their research. They signpost to NIHR Research Design Service, and NIHR INVOLVE guidance on their website. CRUK is part of the shared commitment and use the UK standards.
NIHR	£1.2bn (includes research and infrastructure).	£1.7m on Centre for Engagement and Dissemination. Additional spend on Research Design Service across the UK. Whilst this is not stated anywhere, in our experience, NIHR will fund up to 10% of research funding for PPIE.	PPI is assessed within all NIHR research funding.	Newly introduced. Programme Development grants – Developing innovative, inclusive and diverse public partnerships. 500K fund, grants of £50–150K.	A central team based within the Centre for Engagement and Dissemination, including a Director of Public Voice. PPI Leads/Teams within all infrastructure grants e.g. NIHR Biomedical Research Centres, NIHR Applied Research Collaborations. 2 PPI staff in Head Office. Public involvement in grant guidance, assessment and decision making is led by Grants Management staff.	NIHR convenes a collaborative network which includes joining PPI Leads up across infrastructure, communicating updates and knowledge, drawing on best practice and encouraging active involvement through e.g. completion of surveys/examples.
Parkinson's UK	£8m	Unknown	Parkinson's UK have an expectation for PPI within most funding applications, including non-clinical project grants. For drug accelerator awards there is no PPI expectation.	No	No	

1. Case studies with relevance to MRC challenges

Case study E

Public involvement in research funding processes across non-clinical and clinical research

Parkinson's UK

Introduction and context

Parkinson's UK believes that the feedback from people affected by Parkinson's makes a difference and improves the way the charity does things for people affected by Parkinson's. Involving people living with Parkinson's in research funding decisions lets the Parkinson's community know that they are being listened to and that they have a say in the research being funded by the charity.

Parkinson's UK has involved lay grant reviewers in its funding decisions, across all schemes for around 20 years. People affected by Parkinson's have also been involved in shaping the charity's research strategy, via the Research Strategy Board. Through reflective practice and evaluation, this work continues to improve, serving the mission of Parkinson's UK to improve life for everyone affected by Parkinson's.

Public involvement at Parkinson's UK is led by two full time members of staff, who work in public facing roles. Public involvement in grant funding is led by the research grants team, who have developed knowledge skills and expertise in involving people affected by Parkinson's in reviewing grant applications. Parkinson's UK funds approximately £8m in medical research annually across four main schemes:

1. Project grants – includes both clinical and non-clinical research (PPI section in application form)
2. Non-drug approaches – includes mostly clinical/ applied research (PPI section in application form)
3. Drug accelerator awards – includes non-clinical research (Lay summary request only within application form)
4. Virtual Biotech projects – involves people affected by Parkinson's in review and panel meetings

Parkinson's UK believes the value and strength of the lay grant reviewer role is that the personal experience of living with Parkinson's is brought to the research grants funding process. In the early days of lay involvement in funding, Parkinson's UK found that many of the lay grant reviewers were retired scientists or had a scientific background. The comments from this group of people could often be more about the science aspects of grants and not about their priorities as a person living with Parkinson's. This occasionally undermined the role of the lay grant reviewers and made it less meaningful, as it was difficult to share such comments with applicants when the comments on the science could sometimes be inaccurate or not sufficiently up to date.

Case Study E

Through consultation and refinement, Parkinson's UK has developed approaches and processes to support meaningful involvement in grant funding. This has included training courses, specific lay grant reviewer review forms – tailored to the perspective of people living with Parkinson's – and more detailed plain English sections of grant applications so lay grant reviewers can fully understand the applications.

Below is a summary of some key elements of their approach. Parkinson's UK has offered to share their learning including documentation with the MRC as a follow up to this review.

Key themes in how they work

Public involvement is considered and applied across the entire organisation – It's embedded in their culture. In terms of funding, all grant applications have sections dedicated to the involvement of people affected by Parkinson's.

Continuous improvement – In a similar way to funding itself, public involvement is continually reviewed and improved to create the most impact possible. There is a debrief and evaluation process after each funding round. We regularly meet with our involvement colleagues to share experience and best practice in the field.

Parity – Through a ten point scoring system, and two different roles for lay reviewers, the input of people affected by Parkinson's has an equal influence on the funding decision. The scientific score, lay score and combined score are presented to the panel members within the funding meeting. The charity will only fund the highest quality of science, so if there is an application that the lay grant reviewers like, but has low scientific merit, the charity provides detailed scientific and lay feedback so the applicants can improve future applications and possibly resubmit.

Adding value and removing tensions – Following consultation with the lay grant reviewers, the charity decided that for project grants, which could be non-clinical or clinical, lay grant reviewers don't review applications at the pre-proposal stage. This ensures that lay grant reviewers are using their valuable time and expertise only to review full applications that are potentially fundable from a scientific perspective. In contrast, for the non-drug approaches scheme, lay reviewers are involved in pre-proposal and full application review where they can offer useful insights from lived experience. The charity states that applicants must work with people affected by Parkinson's in the development of an application for this scheme and, if successful, throughout each stage of the research process. Patient and public involvement is essential in the non-drug approaches grant scheme.

Case Study E

Clarity in process and documentation: This includes:

- a) Supporting the writing of plain English summaries – Parkinson's UK worked with researchers and people affected by Parkinson's to break this down into sections
- b) Lay-review forms which are very focused, including asking about:
 - the importance of the research to people affected by Parkinson's – including any perceived benefits of the proposed research and whether it addresses the priorities and needs of people living with Parkinson's
 - whether any plans for participation are well thought out, including any practical issues that should be considered when involving people affected by Parkinson's
 - the plain English summary – does it include sufficient information on the background and purpose of research, whether the language used is appropriate.
- c) A scoring system with clear guidance and descriptors for both lay review and scientific review. Public involvement assessment is included in both.
- d) The agenda is tailored for each panel meeting with clear opportunities for lay review coordinators to present their summaries and comments.
- e) Expectations of grant panel members – including a requirement to use sensitive and considerate language as people affected by Parkinson's are taking part in the meeting, especially as emotive issues may come up during discussions.
- f) Terms of Reference and role descriptions – for all involved. For a lay reviewer, it is essential to have a clear remit of role and expectations of behaviour standards within the role, enabling the charity to address instances where comments may not be constructive, and enabling the option to suggest alternative volunteer roles that may be more suitable. It is also crucial to have awareness and adhere to volunteering best practices.

The charity provides information to panel members on issues to consider when involving people affected by Parkinson's in reviewing and panel meetings, and the panel Chair is very well briefed for each meeting. The charity is considering holding specific virtual sessions on this for panel members.

Roles to meet the purpose – Parkinson's UK have developed at least 3 distinct roles for lay reviewers within their funding:

1. Lay grant reviewers – Parkinson's UK maintain a pool of approximately 100 reviewers, and request 3–4 different lay reviews per application.
2. Lay review coordinators – create a balanced summary of the opinions of approximately 3–4 lay reviews and present them at grant funding panel meetings. There are currently 10 lay review coordinators.
3. Scientists with Parkinson's – A new approach based on the needs of the Drug Accelerator Award scheme in terms of reviewing more technical/specialist information. This volunteer role provides opportunities for people affected by Parkinson's who have a scientific background to use their professional knowledge and expertise to comment on the science in grant applications, an opportunity that was not available before.

Case Study E

Finally, Parkinson's UK has begun to consider how and who should be reviewing equality, diversity and inclusion within their grant applications – both in terms of diversity of the research team, and within research participation. They have introduced a question within all grant applications which is currently assessed by scientific reviewers. The charity will consider how to scale this up to include assessment by both lay and scientific reviewers.

How could this case study support the MRC?

Parkinson's UK has a significantly smaller funding envelope than the MRC as well as a focused area of research and patient population. However, their approaches could be scaled up and implemented across the MRC. This case study is particularly helpful in considering a potential maturity model for introducing public involvement into grant funding processes. Most importantly, it demonstrates how an organisation can embed public involvement at the centre of its culture, but create differing expectations of researchers by scheme or topic. It provides options for flexibility in assessing public involvement, and the differing remits of lay review vs. scientific review. Through establishing clear processes and expectations, MRC can learn from the expertise in managing tensions across public and academic members within funding committee meetings. Finally, the model of grant managers with involvement expertise, and the FTE of public involvement practitioners compared to the investment provides some measure of investment required to staff involvement across a funding organisation.

There is a lot of reference material available on the website. Parkinson's UK is open to supporting the MRC and sharing documentation and learning. Contact: Michelle Bendix.

Please also see Scoping review Example 8 on page 34.

Scoping review

2. Scoping review

This section provides a scoping review of both peer-reviewed and grey literature, undertaken in February–March 2022. Grey literature includes printed publications and information from websites/social media etc.

2.1 Process and Methodology

A Vocal Associate, Laura Thomas, delivered the Scoping review.

Vocal worked with the MRC Project Team and the External Advisory Group to co-produce a list of categories relevant to the non-clinical research environment as follows:

- General
- Principles and Values about the purpose of involvement in non/pre-clinical
- Involvement in pre-clinical research (design and delivery)
- Involvement in clinical research (design and delivery)
- Involvement in research priority setting
- Involvement in research funding
- Involvement in research strategy
- Involvement in involvement strategy
- Involvement in research policy
- Involvement in ethics
- Involvement in governance
- Involvement in communications
- Involvement in engagement
- Involvement in evaluation or measuring impact
- Involvement in training and development.

Scoping review

2.1 Process and methodology

For each sub-group, a list of associated keywords was made.

TABLE 2: Scoping review subgroups and keywords		
Subgroups	keywords	
General	Involvement Participation Engagement PPI PPIE Including Working with Collaborating with Co-development Co-design Co-production	Co-research Inclusive research Patients Carers Patient/Public Partners Public contributors Lay public General public Service users Lay representatives Lay members
Involvement in pre-clinical research (design and delivery)	Non-clinical Basic research/science Discovery medicine/science	Fundamental research Laboratory research Blue sky research
Involvement in clinical research (design and delivery)	Clinical research/science Translational research/ science Applied health/ research	
Involvement in research priority setting	Research priorities Research questions	
Involvement in research funding Funding Calls, Applications and Quinquennial Reviews	Funding panel Funding committee Funding review Grant (synonym for funding) Award	
Involvement in ethics	Research ethics committee Responsible Research and Innovation (RRI)	
Involvement in governance	Steering Group/Board Oversight Advisory Executive	
Involvement in communications	Media Marketing Promotional Information	Knowledge exchange Broadcast Social media (various channels) Blog(ging)
Involvement in engagement	Dissemination Events Science communication	
Involvement in training and development	Capacity building Capability Skills development	

Scoping review

2.1 Process and methodology

The MRC Project Team and External Advisory Group were asked to give suggestions for examples from relevant organisations and projects. The following organisations were suggested. This is not intended as a comprehensive list.

- Alzheimer's Society
- Animal Research Nexus
- Autistica Research
- British Paediatric Surveillance Unit
- Cancer Research UK
- Crohn's and Colitis UK
- EAVE – Early Pandemic Evaluation and Enhanced Surveillance of COVID-19
- Genomics England
- Great Ormond Street Hospital
- Health Data Research UK
- Health Foundation
- Health Research Authority
- INCLUDE Project – NIHR
- James Lind Alliance
- NIHR
- National Office for Research Ethics Committees
- Parkinson's UK
- Rare Disease UK
- Translational Cancer Network
- UKRI
- Usemydata
- Versus Arthritis

Papers and reports that were suggested were incorporated into the long list of References (see Section 4 below). This work continued throughout the period of the project and further useful examples of good practice have been added to the Further Reading & Toolkit list in the main report.

A range of different search tools were used to identify relevant papers using a combination of search terms based on the keywords. The tools included Google Scholar and databases such as Medline via OVID. Once suitable papers were identified, references and citations were searched in order to identify further relevant studies or examples. The long list of references contains papers identified through the search process and following feedback and recommendations from the External Advisory Group.

Drawing on the [UK Standards for Public Involvement](#), we co-produced evaluation criteria by which to assess examples for this landscape review. These criteria were reviewed by the Vocal Team and External Advisory Group.

Scoping review

2.1 Process and methodology

Theme	Description	Key questions
Diversity and inclusion	<p>This theme considers when how and which public contributors were recruited, how researchers/practitioners communicated with them and whether they created inclusive and accessible practices.</p> <p><i>Based on the 'inclusive opportunities' and 'communications' NIHR standards.</i></p>	<ul style="list-style-type: none"> ■ How were the public contributors recruited? ■ How diverse is the involvement? Were any barriers to involvement reported/addressed? ■ Was feedback on the aims and outcomes of the research clearly communicated to the public contributors? ■ At what point in the research cycle were public contributors involved in the research? ■ Did researchers/ practitioners communicate with public participants in an inclusive way?
Collaboration and co-creation	<p>This theme focusses on how the researchers and public participants worked together as part of the research process.</p> <p><i>Based on the 'working together' and 'support and learning' NIHR standards.</i></p>	<ul style="list-style-type: none"> ■ How were the public contributors involved in the research? ■ Was there effective collaboration between the different stakeholders? ■ Did researchers have the support they need to work with public contributors? ■ Were the public contributors included in developing and delivering resources and activities? ■ What were the practical arrangements for working together? E.g. were the public contributors able to influence the terms of their involvement or was this decided by the research team?
Influence and impact	<p>This theme examines the influence the public contributors had on the research, and the impact of involvement on the research and researchers.</p> <p><i>Based on the 'governance' and 'impact' NIHR standards.</i></p>	<ul style="list-style-type: none"> ■ Did the public contributors have influence and a voice when it comes to the research undertaken and the identification of impact? How was impact identified and measured? ■ Did researchers, public contributors and practitioners reflect on their experiences and were outcomes acted on/shared? ■ What was the impact of involvement on public contributors? Did the research team gather feedback and act on it? Were public contributors involved in evaluation as partners? ■ What was the impact of involvement on the research and researchers? ■ Since the initial project have there been any follow-up reporting or outputs showing longer term impact or influence?

Scoping review

2.1 Process and methodology

Limitations of the scoping review

This review provides examples of public involvement across the research environment, and a wealth which include or focus on non-clinical research. However, it's worth noting the limitations of this approach. Firstly, a significant amount of public involvement practice is never published, and the dearth of peer reviewed literature is widely acknowledged. In addition, whilst there are emerging scoping reviews summarising the benefits and challenges of public involvement in pre-clinical research (Fox et al 2021, Carroll et al 2021), some/most publications focus on project delivery, excluding e.g. diversity data, accountability across partner organisations, resourcing, governance etc.

Finally, the methodology of this work was established to identify 25 examples across the breadth of the subgroups and search terms. Therefore there may be very good examples which weren't selected here as they would duplicate another example based on the selection criteria. Where we have identified additional examples, these are noted in the References section.

Scoping review

2.2 Overview of selected examples

The resulting summaries included a discussion of the research context and the approach to patient or public involvement. In some cases, the examples selected featured organisations rather than individual studies and these were chosen to highlight particularly effective approaches. The table below lists the examples and provides comment on why they were selected.

TABLE 4: Summary of scoping review examples		
Example	Title	Comment on selection of example
1	Cloudy with a chance of pain	PPI contributors involved in all phases of the project, from application to dissemination.
2	Of Mice and Dementia	Introduction of PPI contributors as a result of the funder which had a significant impact on the research and researchers.
3	The MAGIC (Magnetic Resonance Imaging in Paediatric Constipation) study	Involvement of children and young people throughout the phases of research.
4	UK Coronavirus Immunology Consortium (UK-CIC)	Broad-ranging and timely involvement across many different aspects of research.
5	Involvement in fundamental genomics psychiatric research	A detailed study of the barriers and challenges to PPI in genetics research.
6	ReIMAGINE: a prostate cancer research consortium	An example showing the impact of having dedicated PPI support for the researchers and the impact of partnership working.
7	Patient oriented research in preclinical mental health research in Canada	A discussion of the wide ranging impacts on PPI contributors and researchers of involvement in preclinical research.
8	Parkinson's UK	Focus on the PPI structures and partnerships supported by Parkinson's UK.
9	HIDDEN study and the application of NIHR standards	Example of using the NIHR standards to reflect on the impact of involvement on a research study.
10	PPI in a European translational research project	Large-scale international collaboration and how they embedded PPI across work packages, along with a discussion of the impact on the research being undertaken.
11	Involvement in Genetics and Outcomes Research	A look at undertaking detailed discussions with PPI contributors at the outset of a preclinical research project.
12	The role of patient advocacy organisations in neuromuscular disease R&D	Example focusses on the impact on research individual patient advocacy groups can have, especially in under-researched and lower priority fields. A more open-ended model of drug development is proposed.
13	Generation Scotland: consulting publics and specialists at an early stage in a genetic database's development	An example of detailed discussions with PPI contributors as part of the set-up of an extensive genetics database.
14	Patient Voice in Arthritis Research (PVAR)	An example of a co-design approach to enabling discussions between researchers and PPI contributors. There was a particular focus on equity in the engagement activities and training for the researchers.
15	Oxford Neuroscience, Ethics and Society Young People's Advisory Group (NeurOx YPAG)	The establishment and impact of a young people's advisory group with an emphasis on co-design approaches.

Scoping review

TABLE 5: Summary of scoping review examples (continued)		
Example	Title	Comment on selection of example
16	The importance of clinician, patient and researcher collaborations in Alport syndrome	This example highlights how different researchers and patient organisations can effectively collaborate.
17	Evaluation of a Partnership Approach to Translating Research on Breast Cancer and the Environment	Helpful example where both public contributors and patient organisations were included in involvement activities.
18	Selective patient and public involvement: The promise and perils of pharmaceutical intervention for autism	A reflective example on the challenges of PPI, particularly in relation to “selective involvement” when working with only one main patient group and the issues that arise.
19	PPI in research: a reflection from early stage researchers	Example of the experiences of early career researchers with a focus on PPI training and its impact
20	A protocol for the evaluation of the process and impact of embedding formal and experiential Public and Patient Involvement training in a structured PhD programme	Example of incorporating PPI into a doctoral training programme. This research is currently ongoing but is an interesting model to review and see what lessons can be learned and whether there are some initial results the researchers can share.
21	Public deliberation in the use of health and care data	This example looks at the approach of engaging with members of the public to gather perspectives on the use of medical data in research. There are many different aspects within the full report which is relevant to the work with MRC. Further information on this topic can be drawn from Health Data Research UK who have provided guidelines and support for researchers in this field.
22	Training for PPI contributors	This example focusses on the provision of a training module for researchers on PPI based on the experiences of Crohn’s and Colitis UK. It would be interesting to know if they have considered a version of this for health data researchers.
23	Involvement in Animal Research	This example provides some highlights of a wide-ranging study focussing on involvement in animal research. It incorporates the perspectives of PPI contributors, researchers, PPI professionals and funders. It identifies challenges and barriers and provides advice and guidance around best practice.
24	Co-developing training for researchers with patient involvement	An example of the co-production of training for translational researchers
25	The reported impact of public involvement in biobanks	A review of the impact of involvement of PPI on biobanks. Provides summaries of the types of PPI used in biobanks and draws conclusions about the impact and makes recommendations to improve collaboration between PPI contributors and researchers.

TABLE 5: Overview of selected examples. The following table summarises the subgroups linked to each example.

Example No. and Title	Principles & Values about the purpose of involvement in non/pre-clinical	Involvement in													
		Pre-clinical research (design & delivery)	Clinical research (design & delivery)	Research priority setting	Research funding	Funding Calls, Applications and Quinquennial reviews	Research strategy	Involvement strategy	Research policy	Ethics	Governance	Communications	Engagement	Evaluation or measuring impact	Training & development
1 Cloudy with a chance of pain		●													
2 Of Mice and Dementia		●			●	●				●					●
3 The MAGIC (Magnetic Resonance Imaging in Paediatric Constipation) study		●								●		●			
4 UK Coronavirus Immunology Consortium (UK-CIC)		●	●	●					●		●	●			
5 Involvement in fundamental genomics psychiatric research	●	●		●								●	●		
6 ReIMAGINE: a prostate cancer research consortium			●									●	●		
7 Patient oriented research in preclinical mental health research in Canada	●	●		●											●
8 Parkinson's UK	●	●	●	●	●	●	●	●	●	●	●				●

TABLE 5: Overview of selected examples. The following table summarises the subgroups linked to each example.

Example No. and Title	Principles & Values about the purpose of involvement in non/pre-clinical	Involvement in														
		Pre-clinical research (design & delivery)	Clinical research (design & delivery)	Research priority setting	Research funding	Funding Calls, Applications and Quin-quennial reviews	Research strategy	Involvement strategy	Research policy	Ethics	Governance	Communications	Engagement	Evaluation or measuring impact	Training & development	
9 HIDDEN study & the application of NIHR standards			●												●	
10 PPI in a European transnational research project		●													●	
11 Involvement in Genetics & Outcomes research		●		●						●					●	
12 The role of patient advocacy organisations in neuromuscular disease R&D		●	●	●						●						
13 Generation Scotland: consulting publics & specialists at an early stage in genetic database's development		●								●	●	●	●			
14 Patient Voice in Arthritis Research (PVAR)		●					●		●	●	●				●	
15 Oxford Neuroscience, Ethics & Society Young People's Advisory Group (NeurOx YPAG)			●									●				

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16 The importance of clinician, patient & researcher collaborations in Alport syndrome		●	●										●		
17 Evaluation of a Partnership Approach to Translating Research on Breast Cancer & the Environment		●													
18 Selective patient & public involvement: The promise and perils of pharmaceutical intervention for autism		●													
19 PPI in research: a reflection from early stage researchers			●												●
20 A protocol for the evaluation of the process & impact of embedding formal and experiential Public & Patient involvement training in a structured PhD programme			●											●	●

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21 Public deliberation in the use of health and care data		●	●						●	●	●				
22 Training for PPI contributors		●	●		●					●	●				●
23 Involvement in Animal Research		●								●					
24 Co-developing training for researchers with patient involvement		●													●
25 The reported impact of public involvement in biobanks		●	●							●					

Scoping review

2.3 Selected examples in detail

1. Cloudy with a chance of pain

Research context: People have regularly reported changes in their experiences of pain as a result of changes in the weather but there has been inconclusive evidence. This study recruited thousands of people with chronic pain to record their experience of pain via an app. Researchers were then able to link this to the weather based on their GPS location.

Diversity and inclusion: A Patient and Public Involvement (PPI) group was established and active throughout all phases of the project. One PPI contributor was involved as a co-applicant for a grant and co-author of a peer-reviewed paper (Dixon et al 2019). There were 8 members of the group with limited information available on the individuals. They were recruited from local partners and received remuneration for their time. There was limited information available on how and what the researchers communicated to the PPI contributors.

Collaboration and co-creation: The PPI group made various contributions to the research and the development of the app in particular:

- "Their remit was to provide views based on personal experience of musculoskeletal conditions to shape the research questions and methods, help design the app, and assist in interpreting emerging results." (Reade et al 2017).
- "During the feasibility study, patients positively influenced the wording and display of questions within the app". (Dixon et al 2019).
- In addition to the patient involvement group, study participants took part in focus groups and interviews to help inform the "codesign of the app" (Reade et al 2017).

There was limited information about the practical arrangements of the collaboration, only that the PPI group met every three months during the project. There was no comment on whether the researchers were given the support needed to work with the PPI group.

Influence and impact: In addition to the development of the app, the PPI group were involved in the analysis and interpretation of results along with the communication of the research to different audiences. Members of the group were involved in "media broadcasts at study launch and subsequent public engagement activities, explaining why the research question was important to them and relevant to patients with long-term pain conditions." (Dixon et al 2019). Within the published articles there was no discussion of the impact of involvement on the PPI group or the researchers.

Website and social media links

<https://www.cloudywithachanceofpain.com/>

<https://www.facebook.com/cloudypain/>

<https://twitter.com/cloudypain>

Scoping review

2.3 Selected examples in detail

Article references

Dixon, W.G., Beukenhorst, A.L., Yimer, B.B., Cook, L., Gasparrini, A., El-Hay, T., Hellman, B., James, B., Vicedo-Cabrera, A.M., Maclure, M. and Silva, R., 2019. How the weather affects the pain of citizen scientists using a smartphone app. *NPJ digital medicine*, 2(1), pp.1-9.

Reade, S., Spencer, K., Sergeant, J.C., Sperrin, M., Schultz, D.M., Ainsworth, J., Lakshminarayana, R., Hellman, B., James, B., McBeth, J. and Sanders, C., 2017. Cloudy with a chance of pain: engagement and subsequent attrition of daily data entry in a smartphone pilot study tracking weather, disease severity, and physical activity in patients with rheumatoid arthritis. *JMIR mHealth and uHealth*, 5(3), p.e6496.

Subgroups

- Involvement in pre-clinical research (design and delivery).

Scoping review

2.3 Selected examples in detail

2. Of Mice and Dementia

Research context: Ethics around the use of animals in research, specifically relating to preclinical studies of dementia.

Diversity and inclusion: The PPI contributors came to work with the project as a result of a fellowship award from the Alzheimer's Society (AS) to one of the researchers. Members of the AS Research Network volunteer group all have a personal experience of Alzheimer's or dementia. The network members were recruited to the project as a result of the first annual monitoring meeting between the project and the Alzheimer's Society. AS works to include members of their volunteer group in these meetings and in these meetings the researcher had their first experience where "preclinical research was directly informed by the 'end-user'" Tamagnini et al (2018). There is insufficient information available on the contributors to comment on the diversity of those involved or the communication between researchers and contributors.

Collaboration and co-creation: The PPI contributors were involved in the early phases of research onwards. This included contributing to the research questions and resulting methodologies. They provided a range of advice and guidance to the researchers. There was limited information on the practical arrangements of the collaboration.

Influence and impact: Through the involvement of the PPI contributors, the researchers reflected that they had been able to develop their own skills and knowledge as a result of the relationships they developed. One particular volunteer was "a retired Royal Navy officer and has a strong scientific background: his feedback was invaluable for both making the science more translatable and developing leadership skills of the research team. These skills are often an issue amongst researchers, as the science life usually leads the researcher from mainly focusing on experiments and analysis (in the postdoctoral years) to having to lead a group of people, with little or no formal education on how to manage a project." Tamagnini et al (2018). The researcher's felt there had been impacts beyond the intended scope of the collaboration.

Website and social media links

The film can be viewed here: <https://youtu.be/llqBjV69PnU>

Lead author links:

<https://www.reading.ac.uk/pharmacy/staff/dr-francesco-tamagnini>

<https://www.alzheimers.org.uk/research/our-research/research-strategy/ensuring-future-dementia-research/DRL-francesco-tamagnini>

Information on the Alzheimer Society's volunteer network:

<https://www.alzheimers.org.uk/form/research-network-applications>

Scoping review

2.3 Selected examples in detail

Article references

Tamagnini, F., Cotton, M., Goodall, O., Harrison, G., Jeynes, C., Palombo, F., Tomkow, J., Tomkow, T., Wedgwood, K. and Welsman, J., 2018. 'Of Mice and Dementia': A filmed conversation on the use of animals in dementia research. *Dementia*, 17(8), pp.1055–1063.

Subgroups

- Involvement in training and development.
- Involvement in pre-clinical research (design and delivery).
- Involvement in research funding.

Scoping review

2.3 Selected examples in detail

3. The MAGIC (Magnetic Resonance Imaging in Paediatric Constipation) study

Research context: Development of a new diagnostic method (gut transit time) to be used with children who experience constipation.

Diversity and inclusion: Children and Young People (CYP) were recruited from the National Institute for Health Research (NIHR) Nottingham GenerationR (Young Persons Advisory Group (YPAG)). The YPAG were involved throughout the life-cycle of the project. The project reported having included members across all age ranges, different ethnicity and socioeconomic background, some from the general population and schools, some from out-patient clinics and some from participants to research studies" (Abrehart et al 2021). No barriers to involvement have been shared.

Collaboration and co-creation: When meeting with the YPAG, the sessions were designed to be engaging and to "encourage inclusivity and freedom of ideas" (Abrehart et al 2021). CYP were involved in developing ground rules for the sessions. The arrangements for the sessions were led by the researchers but they did try to keep in mind the needs of the CYP and the sessions themselves were "devised by the group facilitators, but directed by the children's own ideas of what they wanted to do" (Abrehart et al 2021).

Influence and impact: The YPAG were able to influence many elements of the study and this continued into the follow-up project (MAGIC2). This included advising on suitable language for communicating with different age groups in addition to advising the researchers and technology designers on their proposed methods. The researchers felt the meetings with the YPAG were a learning experience for them. Feedback was gathered from the members of the YPAG and there were clear instances where the CYP felt they had an impact on the project and on the researchers themselves: "I think there are a lot of things that are changed because of the YPAG" (Abrehart et al 2021).

Website and social media links

<https://www.gastrointestinalmri.org.uk/>

<https://www.gastrointestinalmri.org.uk/ppi/>

<https://generationr.org.uk/>

Article references

Abrehart, N., Frost, K., Harris, R., Wragg, A., Stewart, D., Sharif, H., Matthews, R. and Marciani, L., 2021. "A little (PPI) MAGIC can take you a long way": involving children and young people in research from inception of a novel medical device to multi-centre clinical trial Roald Dahl, James and the Giant Peach (1961). *Research Involvement and Engagement*, 7(1), pp.1–15.

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in ethics.
- Involvement in communications

Scoping review

2.3 Selected examples in detail

4. UK Coronavirus Immunology Consortium (UK-CIC)

Research context: The research being undertaken linked to the development of vaccines for SARS-CoV-2, specifically on the immune system response to the virus.

Diversity and inclusion: A Patient and Public Involvement Panel was established by UK-CIC: “ten members from diverse backgrounds and a range of lived experiences” (British Society for Immunology 2021). This was set up and managed by the British Society for Immunology (BSI). BSI used a “Terms of Reference” document to guide the recruitment to the panel. This document described the panel’s “remit, aims, ways of operating and remuneration”. There was an expectation that panel members would be IT literate and have access to digital devices and an internet connection. The UK-CIC acknowledge this would exclude those without the necessary skills and digital resources. The resulting group were selected so that they would “complement and collaborate well with each other”. The group membership was gender balanced, geographically diverse (representatives came from across the UK). Some members had themselves had COVID-19 and there were those from clinically extremely vulnerable groups. The UK-CIC report acknowledges that the “UK-CIC public health research priorities defined recruitment to the PPI panel” (British Society for Immunology 2021).
Collaboration and co-creation: Monthly meetings took place on Zoom, co-chaired by a panel member and a BSI representative. These meetings would be attended by a different researcher each month who presented and led a discussion with the panel. Updates were also provided from the UK-CIC Principal Investigator. There are not many specific examples of what the panel has impacted on but there is lots of reflection on the impact of the panel, see the following section. The panel seems to have advised on a range of different aspects of research but it does not appear as though they were involved closely with specific projects over a longer period. The structure of the collaboration seemed to be defined by BIS, with researchers attending meetings to get feedback. For many researchers this seemed to be the first time they had collaborated with a PPI panel.

Influence and impact: Two members of the panel were also on the UK-CIC Scientific Board, meaning that patient and public contributors were part of wider strategic and priority setting discussions. The UK-CIC sought feedback from participants and their role evolved throughout the course of their involvement: “Over time, the members of the panel reported feeling more confident and comfortable in asking pertinent questions directly to the scientists. Their confidence grew in putting forward different and new questions they felt were important to be addressed. When global knowledge of COVID-19 expanded, the research undertaken by the UK-CIC progressed and the PPI panel’s responsibilities developed. The panel’s perspectives were vital to place the research in the context of the concerns and needs of the public to meet the changing dynamics of the pandemic” (British Society for Immunology 2021). The panel were able to influence the content of the UK-CIC website and in particular they ensured information on COVID-19 vaccines was accessible (including for those with visual impairments) and that a range of sources of information was available.

The panel members also supported public events held by the UK-CIC. These included live webinars and Reddit AMAs. Feedback was gathered from Advisory and Management board members and this indicated that the PPI panel “had changed their views towards the research agenda of UK-CIC” (British Society for Immunology 2021) and this impact increased over time. Members of the boards indicated they would be more likely to involve PPI in their future research as a result of this experience. One aspect impact on researchers focussed around how to

Scoping review

2.3 Selected examples in detail

communicate their findings to the general public and how to describe the use of patient cohorts and samples. Another related to the benefits of involving public and patient perspectives at the beginning of research projects, with some researchers using the conversations with the panel as a springboard for future research ideas.

The panel were also able to provide insight into the lived experience of patients, encouraging researchers to think of the impact on individuals “rather than just thinking about populations” (British Society for Immunology 2021). Feedback was gathered after every meeting and this was used to inform future discussions and activities. There was a sense of “evolution” of the use of the PPI panel. One area for improvement was identified in relation to training for researchers on the importance of PPI.

Website and social media links

<https://www.uk-cic.org/>

Article references

British Society for Immunology (2021) The impact of patient and public involvement in the UK Coronavirus Immunology Consortium. Available: <https://www.immunology.org/news/the-impact-patient-and-public-involvement-in-the-uk-coronavirus-immunology-consortium>

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in preclinical research (design and delivery).
- Involvement in research priority setting.
- Involvement in governance.
- Involvement in communications.

Scoping review

2.3 Selected examples in detail

5. Involvement in fundamental genomics psychiatric research

Research context: A consortium of university and health organisations in the Netherlands (Genetic Risk and Outcome of Psychosis, GROUP) focussed on fundamental genomics psychiatric research were asked to include patients as part of their research as a funding requirement. The original focus of the research was psychiatric with genomics being introduced over time through a collaboration with US researchers. However there was reluctance to communicate the research to the public as there were many internal “heated and technical discussions” about how to proceed (Baart and Abma 2011).

Diversity and inclusion: The partner organisations involved were included as a requirement of funders and not at the invitation of the researchers. This affected attitudes and relationships at the beginning of the collaboration. PPI contributors came from a partner organisation, Anoksis which is an organisation for people with schizophrenia. The PPI contributors were involved at the beginning of the research collaboration but researchers were reluctant to provide them with information about psychiatric genomics research, especially as some patients themselves experienced schizophrenia. This initial reluctance seems to have been overcome by the involvement of a social scientist who acted as a facilitator between the researchers and PPI contributors. They began with a focus group on what both the researchers and patients wanted to know about schizophrenia.

Collaboration and co-creation: The patient contributors helped to develop a set of research questions linked to their own lived experiences and this was a “a real eye opener for the scientists” (Baart and Abma 2011) as the patient contributors had similar interests to them. The social scientists noted that there was a conceptual shift amongst the researchers: “from a knowledge deficit model to an interactive dialogic model” (Baart and Abma 2011). An effective collaboration was then established (with the continued help of a facilitator) following the initial relationship-building and the attitudinal shift of the researchers. Without the support from the facilitator this would not have occurred. The practical arrangements for working together were then agreed between the patient contributors and the researchers, so the patient contributors had influence on the terms of their involvement.

Influence and impact: The patient contributors were then involved in a range of different activities, from advising on website content to encouraging researchers to hold patient and family conferences to interact with more people affected by schizophrenia. The researchers and patient contributors jointly presented at conferences. The impact of the patient contributors was viewed as extremely positive and the GROUP consortium appointed a facilitator to work half a day a week to support the dialogue. The patient contributors were consulted on their involvement and included in the work reported by Baart and Abma (2011). The scientific findings were communicated to partner organisations and without this collaboration, the implications of this fundamental research may not have been understood by families affected by schizophrenia.

Scoping review

2.3 Selected examples in detail

There was reflection on some of the key concerns around the collaboration. One aspect was around the power dynamics between the researchers and patient contributors. For example expecting the patients with anxiety and social phobias to participate in meetings and to fit into other “normative” practices (Bart and Abma 2011). A second issue was around validity and whether one organisation in the Netherlands was representative of patient perspectives in general, especially in an international collaboration. Thirdly, who should be involved as contributors? In this context, it was asked “Is it the patient with schizophrenia, but also patients with anxiety, depression, and bipolar disorder? And maybe also the siblings of these patients, as their genetic susceptibilities construct them as possible future patients?” (Bart and Abma 2011).

Website and social media links

No recent relevant links found.

Article references

Bart, I.L. and Abma, T.A., 2011. Patient participation in fundamental psychiatric genomics research: a Dutch case study. *Health Expectations*, 14(3), pp.240–249.

Subgroups

- Principles and Values about the purpose of involvement in non/pre-clinical.
- Involvement in pre-clinical research (design and delivery).
- Involvement in research priority setting.
- Involvement in communications.
- Involvement in engagement.

Scoping review

2.3 Selected examples in detail

6. ReIMAGINE: a prostate cancer research consortium

Research context: The research consortium has been working to develop more accurate diagnostic tools to prevent the high prevalence of under-diagnosis, over-treatment and missed diagnoses amongst men in relation to prostate cancer.

Diversity and inclusion: PPI contributors were involved throughout the research process, from grant application to completion. A PPI co-ordinator was appointed to facilitate the dialogue. Prostate Cancer and Movember supported recruitment of members for the PPI sub-committee. These partnerships were particularly important in ensuring a diverse and representative group of people were recruited to the sub-committee. The members had diverse ethnicity and ranged from patients directly affected by prostate cancer to family members of those with prostate cancer. The PPI co-ordinator and a project researcher also sat on the sub-committee.

Collaboration and co-creation: Through a series of initial discussion/focus groups, the public and patient contributors “provided insight into participant preferences with respect to design and management, data collection and analysis, and dissemination of findings” (Green et al 2021). There was patient involvement in the study’s steering group and there was a PPI sub-committee. This committee met every three months and the chair of the PPI sub-committee attended meetings every two weeks with the project team.

Influence and impact: Following the establishment of the sub-committee they were involved in the following: “the committee have reviewed all patient facing documents (e.g. patient information sheet, consent form, invitation letter), developed the patient area on the ReIMAGINE website, advising on design, layout and content. They created the storyboard and scripts for the patient information videos on the website by working closely with the PPI Coordinator and ecancer (a specialist communications agency) and engaged in the production process of the six-monthly newsletter through feedback on both content and design. The Chair also assists with editing the final draft of the newsletter.” (Green et al 2021).

The impact of the PPI sub-committee included the establishment of a Prostate Cancer research group focussing on minority ethnic communities: “This specialist group provides a platform for a greater range of perspectives and allows researchers to access and foster dialogue between this under-represented population of patients and members of the public who wish to be involved with clinical research, in addition to providing an opportunity for their voices to be amplified through sharing their lived experiences – stimulating discussion and promoting greater diversity in research.” (Green et al 2021). There was clear influence on the research itself but unclear as to how the researchers themselves felt about the patient and public involvement. The paper doesn’t report on the impact of participation on the PPI sub-committee members themselves. Please note this example is co-funded by the MRC.

Scoping review

2.3 Selected examples in detail

Website and social media links

<https://www.reimagine-pca.org/>

https://twitter.com/reimagine_pca

Article references

Green, S., Tuck, S., Long, J. et al. ReIMAGINE: a prostate cancer research consortium with added value through its patient and public involvement and engagement. *Res Involv Engagem* 7, 81 (2021). <https://doi.org/10.1186/s40900-021-00322-w>

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in communications – patient facing materials, and website, newsletter and videos
- Involvement in engagement.

Scoping review

2.3 Selected examples in detail

7. Patient oriented research in preclinical mental health research in Canada

Research context: This study looks at the impact of patient involvement in laboratory-based mental health research in Canada, specifically a study focussed on antidepressants.

Diversity and inclusion: The paper authors acknowledge the “stigma” experienced by those diagnosed with mental health issues and that they “encompass a wide range of people, that can include clinicians and researchers. They observed that there are no boundaries between “patient”, “clinician”, and “researcher”.” (Johnston et al 2021). PPI contributors were recruited via partners and individual recommendations and this seems to have been a reactive process rather than a proactive one, at least initially. PPI contributors partnered with the researchers throughout the lifetime of the research project. An advisory committee was established, consisting of 6 PPI contributors, 2 researchers, 2 clinicians and 1 person in an administrative position in relation to PPI.

Collaboration and co-creation: The advisory committee met online due to COVID-19 and the agenda and questions were set by both the researchers and the patient contributors. The paper authors noted that whilst the researchers had informal conversations with patients through their careers, it was only when they had support in developing contacts and partnerships that they were able to fully involve patients in preclinical research. PPI contributors have been involved in a range of opportunities, including presenting TED talks and contributing to teaching graduate students and providing feedback on proposed graduate student research projects. These opportunities have led to further partnerships with PPI contributors being involved throughout. In general, this approach is building a positive culture of collaboration within the host university. Their role is summed up as: “Our patient partners have been mentors, guiding us through their lived experiences and issues they have faced inside and outside the medical community, particularly as those who have lived experience with mental health disorders.” (Johnston et al 2021).

Influence and impact: PPI contributors have been involved in “identifying study and research questions, understanding the lab processes, review of results, and knowledge translation” (Johnston et al 2021). There has been an impact on the PPI contributors in terms of improved knowledge of the fundamental science and laboratory experimental practices. There has also been an expressed interest from one person in terms of a career working in an animal care unit, which is a partner in the study. In terms of impact, one PPI contributor helped to shape a new area of research and supported the facilitation of a new collaboration between the foundational researchers and a psychiatrist, opening up a line of inquiry that would not have previously been attempted. In another example, the research team widened the number of behavioural tests carried out in their animal studies due to feedback from a PPI contributor as they had highlighted other depressive symptoms that could be of interest. This research was recently published (Brymer et al 2020). One of the PPI contributors reflected on their involvement and its positive impact on their treatment: “Being a patient partner is part of my personal therapy to stay well after years of treatment resistant depression. The best thing about being a patient partner is to take the mystery out of mental illness, and that has been pivotal to maintaining my wellness.” (Johnston et al 2021). For the researchers there has been the benefit of learning from the public contributors’ lived experiences and also from their professional experience. For example, one of the public contributors who is a lawyer has provided advice and guidance on the administrative processes of the researchers and how to share impact of the collaboration. There also seems to have been increased motivation around the completion of the research.

In terms of barriers, the study has identified the power balance between the contributors and

Scoping review

2.3 Selected examples in detail

the researchers as a factor and they feel “there would need to be equal footing on which the patients and researchers can stand”. Another barrier identified was the technical language used by the researchers. The PPI contributors themselves found it difficult to identify opportunities such as this one. The principle investigator reflected on the impact of patient involvement: “[it] is not only possible within foundational science laboratories, but it has had a big effect in enriching the activities, training and knowledge of all the members of our laboratory (both students and PIs), however there needs to be a series of steps and recommendations that should be followed to foster POR [patient oriented research] in foundational mental health research” (Johnston et al 2021). There are various recommendations around recruitment, relationship development and involvement in preclinical science. These are outlined in more detail in the paper (Johnston et al 2021).

Website and social media links

<https://members.bcsupportunit.ca/patient-council>

Article references

Brymer KJ, Johnston J, Botterill JJ, Romay-Tallon R, Mitchell MA, Allen J, et al. Fast-acting antidepressant-like effects of Reelin evaluated in the repeated corticosterone chronic stress paradigm. *Neuropsychopharmacology*. 2020 Sep;45(10):1707–16.

Johnston, J.N., Ridgway, L., Cary-Barnard, S., Allen, J., Sanchez-Lafuente, C.L., Reive, B., Kalynchuk, L.E. and Caruncho, H.J., 2021. Patient oriented research in mental health: matching laboratory to life and beyond in Canada. *Research Involvement and Engagement*, 7(1), pp.1–11.

Subgroups

- Principles and values about the purpose of involvement in non/pre-clinical.
- Involvement in pre-clinical research (design and delivery).
- Involvement in research priority setting.
- Involvement in training and development.

Scoping review

2.3 Selected examples in detail

8. Parkinson's UK

Research context: Parkinsons UK supports research in both clinical and preclinical settings. They provide advice and guidance to researchers on how to involve patients in a range of different types of research and this can include facilitation of discussions. This example is more focussed on the work done by Parkinsons UK on involvement in general, referring to specific studies where possible.

Diversity and inclusion: Parkinsons UK has a Research Support Network through which they can survey a larger number of patients or recruit a smaller number to work directly with researchers. There are regional groups which researchers can also engage. They have further developed a group of 'PPI volunteers' who have taken part in training in order to work directly with researchers. Patients have been involved in all stages of the research cycle and the mechanisms of how this is managed is discussed in detail in Parkinsons UK (2018).

Collaboration and co-creation: The researchers featured as part of case studies cite the access to the network and the support of Parkinsons UK as an enabling feature of working with PPI contributors.

Influence and impact: In terms of the typical activities the PPI contributors have been involved with, in one specific preclinical example, a small group were recruited to advise at the grant application stage. They advised on the scope of the research and the researchers maintained a correspondence with the patient contributors and intend to involve them in other aspects. These volunteers were paid for their involvement.

"The volunteers' feedback was immensely beneficial for drafting our application. Their involvement made our research aims more relevant for those affected by Parkinson's, both in the proposed outcomes of the study and in the methodological design." (Parkinsons UK 2018).

The researcher in a preclinical example reflected that they saw the benefits of establishing an ongoing relationship from the start rather than the advice on the grant proposal being a one-off. Patient contributors have reported a sense of satisfaction being involved with researchers and that it has given them a focus and something they themselves can contribute positively to that could potentially impact on them and the treatment of their condition.

In a summary paper looking at the experiences across six different studies, the impact on researchers was discussed.

"PPI can:

- "Offer reassurance that what they are doing is of value and therefore a motivation to continue.
- "Help them to think differently about the condition they are studying.
- "Raise questions that researchers may not have thought of
- "Inform the direction of future research".
- "For PPI contributors, involvement in lab based research can:

Scoping review

2.3 Selected examples in detail

- Bring hope for the condition, even if this may be in the distant future
- Help them to feel they are doing something useful
- Make them feel part of a wider community."

Challenges for researchers and PPI contributors were also identified:

- "Worries about group dynamics – e.g. what to do if one person dominates the discussion, what to do if you don't know the answer to a question.
- "Concerns about how many people is 'enough'.
- "Concern about raising people's expectations, when the process of getting research from the lab into practice can take a long time."

"Barriers that might prevent meaningful involvement were seen to be:

- Health
- The terminology that might be used
- A lack of experience of research, and particularly of lab based research
- Poor communications (from the researcher)."

(Hanley et al 2020).

Website and social media links

<https://www.parkinsons.org.uk/research/patient-and-public-involvement-research>

<https://medium.com/parkinsons-uk/people-powered-research-the-impact-of-patient-and-public-involvement-a08773e9d6d5>

Parkinsons UK, Alzheimers UK and UCLH BRC have produced a guide for people interested in lab-based PPI: <https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home>

A description of a visit to a research laboratory from the perspective of a PPI contributor: <https://verbeeldingskr8.nl/sparkinson/sparks/parkinsonian-mice/>

Scoping review

2.3 Selected examples in detail

Article references

Parkinsons UK (2018), Patient and Public Involvement Guidance for Researchers Available: <https://www.parkinsons.org.uk/sites/default/files/2018-11/PPI%20Guidance%20for%20Researchers.pdf>

Hanley, B. Amjad, A., Ratcliffe, N., Smith, A-L., Yu, R. (2020) Patient and public involvement in laboratory based research: Reflections on six studies. Available: <https://drive.google.com/file/d/1Vejrg9Oa3dURUrl4fHydQSsZGSdmBNG2/view>

Subgroups

- Principles and values about the purpose of involvement in non/pre-clinical.
- Involvement in pre-clinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in research priority setting.
- Involvement in training and development.

Scoping review

2.3 Selected examples in detail

9. HIDDEN study and the application of NIHR standards

Research context: Study into the prevalence of deep vein thrombosis amongst cancer patients in hospices.

Diversity and inclusion: It isn't clear how the key PPI contributors (three of whom were co-authors on the paper) were recruited. The opportunity to find additional PPI contributors was advertised via local networks and online but this didn't result in any approaches. The PPI contributors were involved throughout the research process beginning with the development of the research questions. In order to ensure inclusive and effective communication, there was an understanding of the roles of the PPI contributors and this was supported by strong leadership within the wider management group to ensure PPI contributors were included.

Collaboration and co-creation: The PPI contributors were considered to be "partners and team members" (Seddon et al 2021). The PPI contributors supported the development of resources and documents for study participants and the researchers felt this positively contributed to recruiting "informed and diverse participants" (Seddon et al 2021). There was flexibility in the meeting arrangements, which could be face-to-face or remote attendance. Support for PPI contributors with additional needs was reported to have been dealt with on a case by case basis but no specific examples were given. Feedback was given to the PPI contributors on their involvement.

Influence and impact: Researchers were given dedicated time to work with the PPI contributors. PPI contributors were able to take part in training, for example on 'Good Clinical Practice' and ethics. There was no discussion of training provided for researchers. The PPI contributors were involved in communicating impact and findings at conferences and events. The PPI contributors were "involved in reporting, auditing and recording all examples of impact" (Seddon et al 2021). There were various reflections on impact arising from this collaboration, summarised below: "Valuable lessons for best practice were identified in these reports including engaging with PI at the ethics stage and using PI to disseminate results through academic, stakeholder and guideline development meetings. This was an important clinical study with practice changing implications and careful recording of key activities and benefits was therefore put in place." (Seddon et al 2021) The paper discussed in this example is a direct instance of PPI contributors being involved in the evaluation of the experience. The NIHR standards provided a framework for the retrospective review.

Website and social media links

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/hidden-study/>

Article references

Seddon, K., Elliott, J., Johnson, M., White, C., Watson, M., Nelson, A. and Noble, S., 2021. Using the United Kingdom standards for public involvement to evaluate the impact of public involvement in a multinational clinical study. *Research involvement and engagement*, 7(1), pp.1-10.

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in evaluation or measuring impact

Scoping review

2.3 Selected examples in detail

10. PPI in a European translational research project

Research context: International collaborative project (EURO-TEAM) investigating biomedical markers for rheumatoid arthritis (RA) and using both laboratory-based and psychosocial methods of research. There were 13 European universities and 3 SMEs involved in the collaboration.

Diversity and inclusion: PPI was funded and supported by the EURO-TEAM project from the outset of the project. PPI contributors were recruited from a range of partner organisations across the countries involved. 8/9 PPI contributors personally had RA with the ninth being a relative of someone with the condition. A member of the research team was responsible for the co-ordinating the PPI-related work. The PPI contributors were involved in a range of different workstreams with their involvement differing dependent on the needs of the researchers. Training was made available to the PPI contributors depending on what they were involved in. Formal training on PPI was not offered to researchers.

Collaboration and co-creation: The PPI contributors were involved in a range of activities across the workstreams. This included participating in project meetings, contributing to the development of resources aimed at different audiences, the analysis of results and the dissemination of findings.

Influence and impact: The perspective of the PPI contributors was that they had made a greater impact on the non-laboratory research in the project. Some would have preferred additional training and support to be able to engage more fully with the project. The PPI contributors reported a development in their knowledge of the scientific concepts of the research by the end of the project. Being able to develop relationships with the researchers over time was seen as a very positive experience and outcome. Other recommendations from PPI contributors arising from the evaluation was increased feedback on the outcome arising from their contributions. In terms of the researchers, the majority had not worked with PPI contributors before this project. One non-clinical researcher reflected on the input from the PPI contributors: "It has made the project's outcomes more valuable to the RA community, relatives and friends as well as the research community" (Birch et al 2020).

With regards to impact, the researchers agreed that the PPI contributors had made a more substantial contribution to the psychosocial research package as opposed to the laboratory-based work packages. The production of lay summaries in collaboration with PPI contributors seems to have been a common positive outcome for many researchers in the project but there was a recognition that the PPI contributors could perhaps have been involved at an earlier stage in some work packages. The project researchers were positive about working with PPI contributors in future research as they were able to help provide insight into the work being done. In order to support this, researchers suggested that they would benefit from PPI training as part of PhD studies.

Scoping review

2.3 Selected examples in detail

Website and social media links

<https://cordis.europa.eu/project/id/305549/reporting>

Article references

Birch, R., Simons, G., Wähämaa, H., McGrath, C.M., Johansson, E.C., Skingle, D., Bayliss, K., Starling, B., Gerlag, D.M., Buckley, C.D. and Stack, R.J., 2020. Development and formative evaluation of patient research partner involvement in a multi-disciplinary European translational research project. *Research involvement and engagement*, 6(1), pp.1-14.

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in evaluation or measuring impact.

Scoping review

2.3 Selected examples in detail

11. Involvement in Genetics and Outcomes Research

Research context: The establishment of a collaboration focussed on genetics and outcomes research applied to autism.

Diversity and inclusion: The initial phase of the AutGO project (Autism Genetics and Outcomes) brought together researchers, patient groups and other stakeholders in order to discuss the research priorities for the different groups and how to effectively engage with PPI contributors to enhance the final outcome of the research. An advisory board consisting of 33 members met every two months over the course of a year. The participants were: “outcomes and genetics researchers, clinicians, healthcare providers, patients/family members, and community/industry representatives” (Talebizadeh and Shah 2018). This project came about due to the lack of guidance and frameworks for genetics researchers when incorporating the input of PPI contributors when designing studies.

Collaboration and co-creation: This project focussed on extensive discussion of the issues in genetics research and gathered perspectives of a wide range of stakeholders. The aim was to identify the needs of the different parties and understand any barriers. This scoping work also included identifying other partners or facilitators that could support subsequent research phases. In terms of the resources and materials, these seem to have been curated by the AutGO project and presented to the advisory board for comment and discussion. The project was mindful of taking an equitable approach to communication and not only gathered feedback in the sessions themselves but also through surveys. The sessions themselves were evaluated, with feedback gathered from all members of the advisory board, this feedback was used to improve the effectiveness of the sessions and the communication between the different groups.

Influence and impact: Impact on the advisory board members was assessed using a baseline and follow-up survey on their knowledge and skills.

“Feedback from participants indicated their high level of interest on the topics covered, willingness to share personal experiences and to learn other stakeholders’ perspective, as well as appreciation for the educational aspect of the project.” (Talebizadeh and Shah 2018).

The key themes from the discussions of the advisory group were taken forward into the next phase of the project where the discussion focussed on one particular area, autism (Talebizadeh, Shah, & AutGO Working Group 2020). General recommendations were also made to researchers working in genetics research more generally.

Scoping review

2.3 Selected examples in detail

Article references

Talebizadeh, Z. and Shah, A., 2018. Building a bridge between genetics and outcomes research: Application in autism (The AutGO Study). *The Patient–Patient–Centered Outcomes Research*, 11(4), pp.451–462.

Talebizadeh, Z., Shah, A. and AutGO Working Group, 2020. The AutGO Initiative: A Conceptual Framework for Developing Genetics Outcomes Research Hypotheses. *Autism Research*, 13(8), pp.1286–1299.

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in priority setting.
- Involvement in ethics.
- Involvement in evaluation or measuring impact.

Scoping review

2.3 Selected examples in detail

(please note diagram format has been adapted for the purposes of this review)

12. The role of patient advocacy organisations in neuromuscular disease R&D

Research context: Research into neuromuscular disease, particularly drug-related treatments, can take many years and is often overlooked by funders and research organisations.

Diversity and inclusion: VSN is a Netherlands-based patient advocacy organisation set up to provide support for people with neuromuscular diseases (and their families) and to encourage research into neuromuscular diseases. As such the organisation is led by PPI contributors and partners with many different organisations in research, industry and policy settings. The organisation not only operates within their home country but more widely in Europe and internationally. With regards to involvement:

"The VSN actively tries to involve patients in their board, committees, and activities. Legally the association is governed by its members, but in practice only some of them influence the organisation's decision-making."

Collaboration and co-creation: The VSN advocates for a more open-ended and reflective approach to drug development, as opposed to the more traditional linear model. This is summarised in Figure 2 from Boon and Broekgaarden (2010):

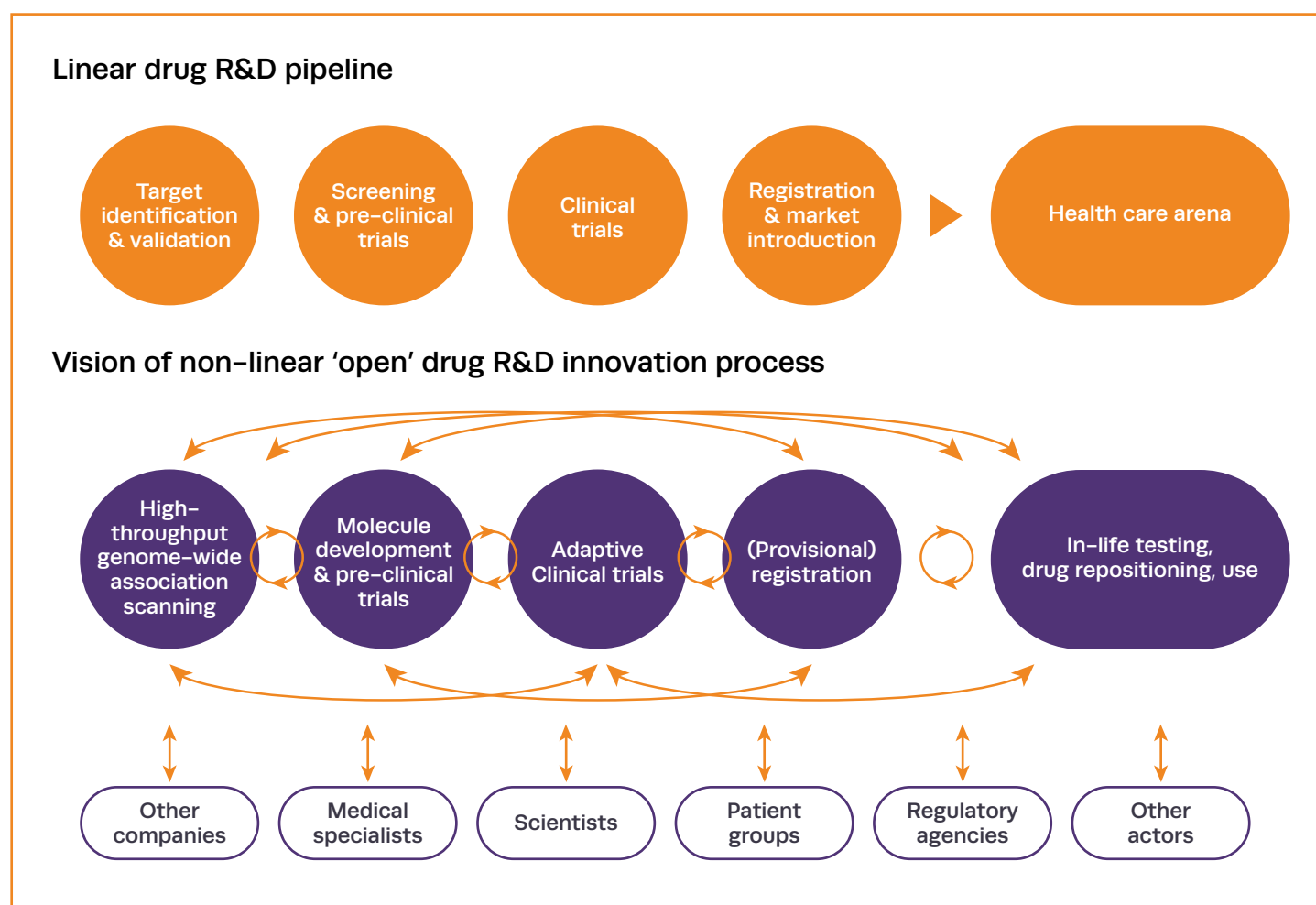


Fig 2: Linear model of the drug innovation process as compared to a more interactive representation

Scoping review

2.3 Selected examples in detail

Influence and impact: VSN works to impact on various areas, including:

- Expectations management: they partner with scientists to communicate latest findings and how this could go on to impact on patients. They support discussion of sensitive topics such as stem cell research.
- Building support: their influencing work with political, research and industrial organisations focusses on demonstrating the need and place for research into drugs for neuromuscular diseases.
- Network building: this organisation has built national and international collaborations to further the case for research into neuromuscular diseases.

Boon and Broekgaarden (2010) summarise the case for working with a partner organisation on drug development:

1. Overcoming market failure – ensuring the development meets the needs of the patients.
2. Employing knowledge of the users and their creative potential: “they not only organised an efficient and effective knowledge exchange between scientists but also tried to convey the wishes, ‘experiential knowledge’ and priorities of patients”.
3. Enhance effectiveness (and speed) of the innovation process: VSN were able to advise on communication of research and “assisting with and initiating clinical trials”.
4. Ethical and social debates in society.
5. Increase democratic value of innovation processes: this refers to the involvement of patients and public contributors.

Website and social media links

<https://treat-nmd.org/organization/spierziekten-nederland/>

<https://www.spierziekten.nl/>

<https://twitter.com/spierziekten>

Article references

Boon, W. and Broekgaarden, R., 2010. The role of patient advocacy organisations in neuromuscular disease R&D—The case of the Dutch neuromuscular disease association VSN. *Neuromuscular disorders*, 20(2), pp.148–151.

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in priority setting.
- Involvement in ethics.

Scoping review

2.3 Selected examples in detail

13. Generation Scotland: consulting publics and specialists at an early stage in a genetic database's development

Research context: Consultation at an early phase of development for a genetic database development project.

Diversity and inclusion: The PPI contributors were involved in the early phases of a research project. The work was conducted at a time when these were newer concepts and there were various misgivings and misconceptions around using genetics data and there was a focus on gathering impressions and attitudes in relation to "social, legal and ethical issues" (Haddow et al 2008).

Collaboration and co-creation: 17 interviews were undertaken with "specialists", described by Haddow et al (2008) as "geneticists, lawyers, theologians, social scientists and clinicians". 10 focus groups were then run and these were chosen to be diverse: "Groups were purposively sampled and chosen to reflect a range of demographics (gender, ethnicity, and age), interests (patient, voluntary and civic groups), and localities (rural or city)." (Haddow et al 2008). These two groups were worked with separately to each other, so there was no natural interaction as part of this project. Instead, Haddow et al 2008 compared and contrasted the findings from the two groups.

Influence and impact: There were commonalities in the issues arising between the researchers/specialists and the PPI contributors, in particular: "despite varying knowledge, experience and awareness of GS, there are ethical, legal, social and political concerns that appear to be embedded in such enterprises regardless of research design, timing, sample and methods" (Haddow et al 2008). The authors reflected that in the early phases of research, "open-ended dialogue does not spontaneously arise" therefore this is something to be facilitated. There were some aspects (e.g. governance) where the specialists were more comfortable answering questions than the PPI contributors, due to their prior knowledge and experience. Beyond the discussion of the issues, the PPI contributors were able to share their views on how the wider public should be engaged with when informing them about the project.

Website and social media links

<https://www.ed.ac.uk/generation-scotland>

Article references

Gill Haddow , Sarah Cunningham-Burley , Ann Bruce & Sarah Parry (2008) Generation Scotland: consulting publics and specialists at an early stage in a genetic database's development, *Critical Public Health*, 18:2, 139-149, DOI: 10.1080/09581590701824086

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in ethics.
- Involvement in governance.
- Involvement in engagement.
- Involvement in communications.

Scoping review

2.3 Selected examples in detail

14. Patient Voice in Arthritis Research (PVAR)

Research context: Preclinical arthritis research.

Diversity and inclusion: Research seminar was held as part of World Young Rheumatic Disease (WORD) Day. 15 young people living with arthritis (aged 10–20) and part of the Irish Children's Arthritis Network (iCAN) took part in the seminar. They were joined by a mentor and two parents. The aim for the event was to discuss current research, for the young people and researchers to have time to meet each other and to encourage the young people to consider undertaking their own citizen science project.

Collaboration and co-creation: Co-design approach with PPI contributors being able to influence all aspects of their interaction, including the location, topics and format. Researchers were given the role of facilitators in their groups and did not know what the activities were, therefore they had to work collaboratively with their group. The event was facilitated by partner organisations with support being provided to researchers.

Influence and impact: Prior to the event, the researchers used the PPI Ready: Researcher Planning Canvas to review their skills and identify any barriers. The main issue identified was in relation to lack of experience talking to a younger audience. Support was offered to researchers ahead of the event and this resulted in a partnership with a local school where researchers could get feedback on their presentations and develop the content. The impact on researchers was an increased confidence speaking to this age group. With regards to the young people, the siblings who attended gained a better understanding of the research going on in relation to their family member's condition and for those experiencing arthritis this was an opportunity for them to develop their knowledge and provide feedback to researchers on their opinions of how to improve current research. Researchers and members of iCAN have expressed interest to the organisers in continuing the relationship building.

Website and social media links

<https://icanireland.ie/>

Article references

Costello, W. and Dorris, E., 2020. Laying the groundwork: Building relationships for public and patient involvement in pre clinical paediatric research. *Health Expectations*, 23(1), pp.96–105.

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in engagement.
- Involvement in training and development.

Scoping review

2.3 Selected examples in detail

15. Oxford Neuroscience, Ethics and Society Young People's Advisory Group

Research context: NeurOx YPAG is part of an Oxford-led project based in the Neuroscience, Ethics and Society research group. They are affiliated with the BeGOOD project which investigates ethical concerns that the early intervention paradigm might pose for young people with and without mental health diagnoses" (Pavarini et al 2019).

Diversity and inclusion: The YPAG has 30 members aged 15–18 "from a wide range of backgrounds and schools, but with shared interest in ethics and mental health" (Pavarini et al 2019). Participants were invited to apply and then selected. Questions linked to their motivation for joining the group. Applicants took part in a taster workshop to get an idea of the types of activities they would be involved in. The group has so far supported four empirical studies.

Collaboration and co-creation: Pavarini et al (2019) describes the group as "co-producers rather than advisors". The facilitators and members of the group produced a set of principles for working together: responsibility, responsivity and transparency, empathy and acceptance, confidentiality. Some training was provided for group members focussing on providing background to the research and relevant aspects such as data protection. Meetings are consistently structured and open-ended in style.

Influence and impact: In addition to the activities forming the regular work of the group (Typical activities include "substantial contributions to the research concept and design, data collection, and/or analysis and interpretation of results" (Pavarini et al 2019) and result in paper co-authorship) further opportunities are made available and the group members can choose whether or not to engage. These additional opportunities include speaking at conferences. Feedback from group members is regularly sought and acted on, e.g. changes have been made to session style.

Website and social media links

<https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/young-peoples-involvement/neurosec-young-peoples-advisory-group-terms-of-reference/>

<https://begoodeie.com/ypag/>

Article references

Pavarini, G., Lorimer, J., Manzini, A., Goundrey Smith, E. and Singh, I., 2019. Co producing research with youth: the NeurOx young people's advisory group model. *Health Expectations*, 22(4), pp.743–751.

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in communications.

Scoping review

2.3 Selected examples in detail

16. The importance of clinician, patient and researcher collaborations in Alport syndrome

Research context: Alport syndrome is a genetic disorder resulting in kidney disease with other potential impacts on hearing and sight. Research into potential treatments is ongoing.

Diversity and inclusion: A workshop on Alport syndrome was held in Glasgow in 2017 prior to the European Society for Paediatric Nephrology 50th anniversary meeting. PPI contributors came from a number of national patient organisations from around the world. The impression is that this was a researcher-led workshop, which representatives of the patient organisations were invited to attend. No specific information was provided on the PPI contributors.

Collaboration and co-creation: The meeting topics were linked to the current diagnosis and treatment of Alport along with discussion of current research into novel treatments. However, the national patient organisations were able to meet ahead of the main workshop “to discuss how they could better collaborate with each other to provide improved resources and support to patients and encourage research” (Rheault et al 2020).

Influence and impact: Several of the PPI contributors were able to share their own experiences. Researchers acknowledged their role in helping to recruit patients for trials and ensuring there was an understanding of the impact of Alport syndrome and the challenges experienced. National organisations were able to highlight initiatives in their own countries. For example information is available in the UK via the Health Talk website and the role of PPI contributors in generating material for this project was discussed. This workshop was followed up by a patient-led meeting the following year between researcher, industry representatives and PPI contributors.

Website and social media links

<https://healthtalk.org/alport-syndrome/overview>

Article references

Rheault, M.N., Savige, J., Randles, M.J., Weinstock, A., Stepney, M., Turner, A.N., Parziale, G., Gross, O., Flinter, F.A., Miner, J.H. and Lagas, S., 2020. The importance of clinician, patient and researcher collaborations in Alport syndrome. *Pediatric Nephrology*, 35(5), pp.733–742.

Subgroups

- Involvement in preclinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in communications.

Scoping review

2.3 Selected examples in detail

17. Evaluation of a Partnership Approach to Translating Research on Breast Cancer and the Environment

Research context: Research into the environmental factors potentially affecting the development of breast cancer.

Diversity and inclusion: Very detailed description of the method of the study but does not go into detail about how PPI was involved in the research.

Collaboration and co-creation: Lots of references to stakeholders and community members but no clear description of the mechanism for their involvement. There seems to have been annual meetings with the local community which researchers attended and facilitators from the project's outreach team would lead.

Influence and impact: Feedback from the PPI contributors directly contributed to the development of the study, for example, they supported researchers in shaping a priority list of environmental factors to examine. Due to their experiences, the researchers wanted to develop their communication skills in order to describe why they needed to undertake animal research in order to understand breast cancer.

In terms of barriers to involvement, there wasn't a defined role for the PPI contributors and it wasn't clear whether or not feedback was being acted on. There seemed to be less opportunity to impact on the lab-based work with the paper authors describing the reasons for this: it was "a basic science project, [it] was funded to answer specific questions and to conform to a required research design, so opportunities for meaningful community input into project design were not really possible". It did not seem as though the researchers felt there would be helpful contributions from PPI contributors. This may be more down to the recruitment of the PPI contributors, who are most commonly referred to as "community members" but there were also breast cancer patient groups involved, but the paper authors felt there was a distinction between the two in terms of interest and motivation.

Training wasn't provided to the PPI contributors and this resulted in frustration at not being able to answer certain questions they had. There were positive impacts observed: "The participation of community advocates in the research resulted in improved communication between the different stakeholder groups, as well as increased sensitivity to each others' perspectives. The science benefited from community input via community advocates who brought key community concerns to the attention of researchers. Researchers learned how to communicate more effectively their science to the public, thus increasing the likelihood that their findings will improve community health."

Scoping review

2.3 Selected examples in detail

Website and social media links

<https://globalprojects.ucsf.edu/project/bay-area-breast-cancer-and-environment-research-center-0>

Article references

Van Olphen, J., Ottoson, J., Green, L., Barlow, J., Koblick, K. and Hiatt, R., 2009. Evaluation of a partnership approach to translating research on breast cancer and the environment. *Progress in community health partnerships: research, education, and action*, 3(3), p.213.

Subgroups

- Involvement in preclinical research (design and delivery).

Scoping review

2.3 Selected examples in detail

18. Selective patient and public involvement: The promise and perils of pharmaceutical intervention for autism

Research context: The EU–AIMS project is an international collaboration focussed on research into the biological mechanisms of autism and to develop suitable treatments.

Diversity and inclusion: Various PPI activities were included within the collaboration's work. This included Autism Speaks (a parent-led charity) as a co-applicant for a grant and continued as a member of the advisory team. The activity discussed in Russell et al (2018) is around feedback on the research agenda and was led by the collaboration and did not seem to directly involve PPI contributors in its design.

Collaboration and co-creation: Two PPI events were run (one in the UK and one in Denmark) in order to gather feedback on the collaboration's research agenda. EU–AIMS produced a film to prompt discussion and feedback was gathered via surveys sent to those who attended the events. Further responses were sought following feedback that the respondents were diverse enough or representative of the autistic community.

Influence and impact: The article authors were able to identify differences in opinion in relation to the drug treatment of autism, particularly around discussing it as a "disease". This was used to make a point about researchers selectively using feedback from PPI contributors and groups to justify their research approach when it is clear from their study that the community hold a range of opinions. Russell et al (2018) reflected on the use of a video to gather feedback on the collaboration's research: "the video unwittingly created a barrier between the research consortium and the autism community by assuming that intervention was required for people with autism; by objectifying autism as an entity apart from the person; and by commodifying the contributions of autism research participants in an (identity-destroying) pharmacological product, all recognized as barriers to participation in autism research". This shows the importance of reflection and also the impact of involvement with PPI contributors.

The feedback from PPI contributors was gathered two years into a five year project and this should have been undertaken sooner. Especially as the opinions on treatments diverged from the strong support of pharmacological treatments of Autism Speaks who had been the key PPI contributors. The authors urge caution, particularly as PPI guidelines were followed closely, as this resulted in "selective" rather than "inclusive" PPI. Whilst aiming for inclusive PPI was seen as desirable, it is unclear whose responsibility it is to ensure this takes place, particularly as inclusive involvement may weaken the case for carrying out research aiming to develop a commercial product. In order to overcome this, the authors recommend additional requirements and independent oversight from funders along with improved training for researchers which extends to conflict management and resolution

Scoping review

2.3 Selected examples in detail

Website and social media links

<https://www.eu-aims.eu/>

Article references

Russell, G., Starr, S., Elphick, C., Rodogno, R. and Singh, I., 2018. Selective patient and public involvement: The promise and perils of pharmaceutical intervention for autism. *Health Expectations*, 21(2), pp.466–473.

Subgroups

- Involvement in preclinical research (design and delivery).

Scoping review

2.3 Selected examples in detail

19. PPI in research: a reflection from early stage researchers

Research context: MiRoR (Methods in Research on Research) is a training collaboration focussed on improving clinical research by focussing on methodology. Areas for attention include the prioritisation of research questions and the sharing of research findings. The paper discusses the impact of a training event on early career researchers (ECRs). This example is drawn from the ECR perspective.

Diversity and inclusion: The paper authors recognise the importance of the PPI contributions to help shape research that will be relevant to peoples' lived experience. Two PPI specialists presented to a training meeting for ECRs on the benefits of PPI and this prompted various discussions. The motivation for engaging with ECRs is to ensure they "champion meaningful PPI, and to produce more valid and relevant research evidence" (Biggane, Olsen & Williamson 2019).

Collaboration and co-creation: Discussions between the ECRs at the 2017 event in Liverpool (all of whom were undertaking PhD research across many different fields in health sciences, from "public health, pharmaceutical science, statistics, biomedicine, mathematics, to computer science, and linguistics" (Biggane, Olsen & Williamson 2019)) were facilitated, with an emphasis on methods and how PPI can contribute to all stages clinical trial research. It is unclear who the PPI contributors were and how they were recruited to this training event. The second event referenced was held in Split, Croatia in 2018 where funders and patients led discussions on the benefits and challenges of PPI.

Influence and impact: In addition to hearing about patient perspectives, the ECRs were also able to see the impact of patient organisations and how networks can collaborate to deliver research aims. The presenters, a patient and a funder representative, were able to describe difference models of involvement with the ECRs. For example, the funder was able to discuss how PPI is expected at the grant application level and the support available to researchers to embed the practice throughout their research cycle. Following the two events, the ECRs in MiRoR held a journal club where they could discuss using PPI as part of their research. For example, one person was considering how to incorporate PPI when developing a core outcome set. There was a general consensus that the earlier PPI can be included, the greater the benefits would be and for some of the researchers they reflected on changes they would have made to their projects had they had a better understanding of the benefits at an earlier point. For some there were still felt to be barriers for inclusive PPI, particularly where the research was of a statistical nature and in the field of computer science. The concluding recommendation of the paper was as follows: "we believe that PPI should be a fundamental

Website and social media links

<https://cordis.europa.eu/project/id/676207>

Article references

Biggane, A.M., Olsen, M. and Williamson, P.R., 2019. PPI in research: a reflection from early stage researchers. *Research Involvement and Engagement*, 5(1), pp.1–9.

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in training and development.

Scoping review

2.3 Selected examples in detail

20. A protocol for the evaluation of the process and impact of embedding formal and experiential Public and Patient Involvement training in a structured PhD programme

Research context: Four members of a doctoral training programme (DTP) focussed on multi-morbidity (those with more than 2 chronic conditions such as diabetes, arthritis, asthma) established a PPI programme. Incorporating PPI was part of this training scheme and embedded within the ethos of the DTP more generally.

Diversity and inclusion: There have been PPI contributors involved at different stages of this doctoral training programme. The PhD students recruited a PPI panel made up of patients and carers but it is unclear how they were recruited.

Collaboration and co-creation: At the outset of the doctoral training programme an existing PPI panel helped to develop the research questions for the PhD students to consider. The PPI panel set up by the PhD students met 4 times a year to advise on a range of issues arising with the PhD research.

Influence and impact: The four PhD students (areas of research included general practice, health economics, health psychology and pharmacy with collaboration occurring between students) were motivated to establish their own PPI panel as they understood the positive impact this could have. However, they also recognised there were barriers and challenges to implementation and are developing their knowledge and skills in the area as part of their DTP. Alongside the PPI within the PhD students' research, a separate evaluation was undertaken to look at the experiences of the PPI contributors and the impact on the researchers. This evaluation work is currently ongoing.

Subgroups

- Involvement in clinical research (design and delivery).
- Involvement in training and development.
- Involvement in evaluation or measuring impact.

Scoping review

2.3 Selected examples in detail

21. Public deliberation in the use of health and care data

Research context: Medical data can be used in variety of research contexts and settings, including preclinical research to develop new treatments. There are privacy concerns around the use of medical data and this example describes the work done by the OneLondon project to consult with members of the public.

Diversity and inclusion: 100 PPI contributors were recruited to the project to reflect the diversity of London. The overarching aim of the project was to gather feedback on peoples' expectations when it came who should have access to medical data and how it should be used. A company was engaged to recruit the participants and this involved going out into the different areas of London and approaching people in the street. Targets and quotas were set around different groups to ensure diversity of the whole group and to reflect the general population, e.g. with respect to age, gender, ethnicity. Those who took part in the weekend discussions were paid for their time.

Collaboration and co-creation: The facilitated discussion model of the project allowed for continued feedback on the aims of the project itself. The participants took part in 4 days' worth of discussions (over 2 weekends) each day with a different focus. The discussion themes were: "Access and control in health and social care, data use to support planning and quality improvement in health and care and wider public services, the use of data in research and development, public and political involvement in ongoing governance and oversight" (OneLondon 2020a). Many different specialists and researchers gave talks and examples of the use of medical data. All of the talks can be accessed on the OneLondon website.

Influence and impact: The outcome of the discussions was summarised in a report and will inform the development of a policy for the use of medical data which is "legitimate and continues to build trust and confidence" (OneLondon 2020a). There are implications for the use of medical data across all of the four themes. However, the examples used within the research and development theme were all clinical-related. With regards to the impact on the PPI contributors, any feedback gathered was limited to attitudinal changes following participation.

Website and social media links

<https://onelondon.online/citizenssummit/>

<https://www.hdrk.ac.uk/news/public-deliberation-in-the-use-of-health-and-care-data-new-report-from-onelondon-lhcre/>

<https://imperialcollegehealthpartners.com/portfolio/onelondon/>

Scoping review

2.3 Selected examples in detail

Article references

OneLondon, 2020a. Public deliberation in the use of health and care data. Available: <https://www.onelondon.online/wp-content/uploads/2020/06/Public-deliberation-in-the-use-of-health-and-care-data.pdf>

Subgroups

- Involvement in pre-clinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in research policy.
- Involvement in ethics.
- Involvement in governance.

Scoping review

2.3 Selected examples in detail

22. Training for PPI Contributors

Research context: An inter-disciplinary research area, incorporating maths, statistics, computer science and others, health data research uses patient information to address a broad range of research topics. This can involve working with large data sets (Big Data) and incorporate the use of artificial intelligence as part of the research.

Diversity and inclusion: PPI contributors worked alongside staff from Crohn's & Colitis UK, Gut Reaction and Health Data Research UK to develop training materials for people who may be involved in health data research. These contributors were drawn from a Public Advisory Committee (PAC) for Gut Reaction. The training materials were brought together with the NIHR standards in mind.

Collaboration and co-creation: The PPI contributors were given drafts to comment on and were able to feedback their own experiences and opinions on PPI via a survey. Some of the experiences of the PPI contributors were used as part of the module content. One member of the PAC sat on the working group for the training materials and others were involved into testing the materials.

Influence and impact: The module content was co-produced with PPI contributors and reflects a range of experiences people have had in health data research. The content included descriptions of terminology and introduced different types of PPI along with the different stages of the research cycle. This different ways PPI fits into the research cycle was highlighted through different examples and this included research panel assessments and ethics committee. The materials provide an excellent overview of the impact of PPI and highlighted particular examples of impact from the Gut Reaction PAC. Those who complete the module can obtain a certificate.

Website and social media links

<https://twitter.com/CrohnsColitisUK>

<https://www.crohnsandcolitis.org.uk/>

Article references

Crohn's and Colitis UK (2021) Patient and Public Involvement training. Available: <https://www.crohnsandcolitis.org.uk/research/research-involvement-opportunities/training/ppitraining/introduction>

Subgroups

- Involvement in pre-clinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in research funding.
- Involvement in ethics.
- Involvement in governance.
- Involvement in training and development.

Scoping review

2.3 Selected examples in detail

23. Involvement in animal research

Research context: Animal research is essential in many aspects of laboratory-based biomedical research. The Animal Research Nexus is a collaboration of different researchers (including anthropology, geography and history and others) who focus their work on the “complex entanglements between policy and practice that make up the Animal Research Nexus” . This example focusses on the findings published in a March 2022 report on the experiences of including PPI contributors in animal research (Davies, Gorman & King 2022).

Diversity and inclusion: The report was produced as part of a specific study designed to look at the impact of involvement in animal research. The report authors observed a range of different PPI activities and gathered opinions from PPI contributors and researchers. They then carried out 59 interviews (50:50 split between PPI contributors and researchers). This was supplemented by two workshops, one for people involved in ethical review panels and the second included a mixture of different stakeholders.

Collaboration and co-creation: There are many different ways in which PPI contributors can be involved with animal research. Involvement can often begin with engagement at an open day or other outreach activity and result in participation in ethics committees and advisory panels. There were a wide range of experiences reported as part of the study but it did not always seem as though researchers had the support they needed to effectively engage with PPI contributors. In many of the examples, PPI contributors were involved in existing research structures such as ethics committees.

Influence and impact: The report summarises the different perspectives of involvement in animal research and should be read in detail. PPI contributors valued the conversations they were involved in but were unsure as to how much influence they had and “For some, involvement around animal research is an ethical and emotional challenge” (Davies, Forman & King 2022). For researchers, there was a recognition of involvement improving the research but there was a lack of experience in putting it into practice and many identified challenges. Funders reported wanting to see PPI contributors involved but animal research seems to be a particular concern and they were “unsure when and whether these conversations made a meaningful difference to research” (Davies, Forman & King 2022). The impact of PPI contributors seemed to be more around showing “public support for animal research, rather than shaping research to reflect the views of those affected by health conditions” (Davies, Forman & King 2022). The report provides advice and guidance for all of these groups (as well as engagement and PPI professionals) on how to engage with each other on animal research. One of the key conclusions is around the importance of relationship building, something that the report authors found wasn't necessarily supported in current research culture.

Scoping review

2.3 Selected examples in detail

Website and social media links

<https://animalresearchnexus.org/>

<https://twitter.com/AnimalResNexus>

<https://animalresearchnexus.org/projects/engagement-involvement>

Article references

Davies, G., Gorman, R. & King, G. (2022) Informing involvement around animal research. Available: <https://animalresearchnexus.org/publications/informing-involvement-around-animal-research>

Davies, G., Gorman, R., McGlacken, R. and Peres, S., 2021. The social aspects of genome editing: publics as stakeholders, populations and participants in animal research. *Laboratory Animals*.

Gorman, R. & Davies, G. (2019) Patient and Public Involvement and Engagement (PPIE) with Animal Research. Available: https://animalresearchnexus.org/sites/default/files/patient_and_public_involvement_and_engagement_ppie_with_animal_research.pdf

Subgroups

- Involvement in pre-clinical research (design and delivery).
- Involvement in ethics.

Scoping review

2.3 Selected examples in detail

24. Co-developing training for researchers with patient involvement

Research context: Translational healthcare research is concerned with turning lab-based research into treatments for patients. UCL's ACCELERATE project is a collaborative translational research training programme providing skills development for researchers.

Diversity and inclusion: The training materials were developed in partnership between UCL staff and the PPI panel within the UCL Blood and Transplant Research Unit. The staff leading the development of the training were able to partner with an existing PPI panel within their own organisation.

Collaboration and co-creation: The panel provided feedback on existing information within UCL on the reasons for engaging with research. Detailed information wasn't provided on the exact mechanism for the collaboration. However, it is clear the panel were able to have significant influence on the content of the materials.

Influence and impact: The input of the panel resulted in a number of impacts. In relation to the starter document on the reasons for engaging with research, it was updated to include a strengthened case for the impact of PPI and its benefits. It also included the perspective of the PPI panel and what they get from taking part in the research. Guidance was added around language, particularly technical writing and jargon and how tone can affect the engagement. The final training resource incorporates many different perspectives and includes comment on "ethics, research quality, industry, and legal considerations" (Craig 2021). There is an emphasis on relationship building and the investment required in order to make this successful. Personal perspectives from the panel on the benefits of involvement were included.

Website and social media links

<https://www.ucl.ac.uk/school-life-medical-sciences/about-slms/office-vice-provost-health/academic-careers-office/career-schemes/accelerate/accelerate-5>

<https://www.ucl.ac.uk/school-life-medical-sciences/about-slms/office-vice-provost-health/academic-careers-office/accelerate>

Article references

Craig, H. (2021) Co-developing training for researchers with patient involvement. Available: <https://uclpartners.com/blog-post/co-developing-training-for-researchers-with-patient-involvement/>

Subgroups

- Involvement in pre-clinical research (design and delivery).
- Involvement in training and development

Scoping review

2.3 Selected examples in detail

25. The reported impact of public involvement in biobanks

Research context: This research examined in this article is focussed on the impact of public involvement in biobanks. This review examined evidence from thirty one biobanks. Biobanks combine a range of different types of data, usually genetic information alongside personal data and other medical information. Many different types of organisations run biobanks but there are common issues around ethics and legal requirements. .

Diversity and inclusion: An assessment of the level of involvement across the biobanks was made. The paper by Luna Puerta et al (2020) provides detailed information on the different models of how PPI contributors were involved. This ranges from diverse PPI panels being recruited to advise on ethics and governance to adhoc consultations and advice.

Collaboration and co-creation: In general, the review identifies that PPI has been focussed on improving recruitment of participants for the biobanks rather than there being a more fundamental engagement and involvement process in the research itself.

Influence and impact: Whilst there was limited evidence for the impact of PPI contributors on the biobank research, the study found "Broader forms of impact were reported but were vaguely defined and measured" (Luna Puerta et al 2020). The study concludes that impact of PPI needs to be revisited and encourage it to be considered as a "two-way learning process" (Luna Puerta et al 2020). They also recommend investment in support for researchers and PPI contributors in order to effectively engage with each other and understand the benefits of such a relationship. The review did not identify any negative impact of PPI on stakeholders. There was a recognition that there was a lack of the voice of PPI contributors in the papers identified and this limits the full assessment of impact.

Website and social media links

<https://www.ukbiobank.ac.uk/>

Article references

Luna Puerta, L., Kendall, W., Davies, B., Day, S. and Ward, H., 2020. The reported impact of public involvement in biobanks: a scoping review. *Health Expectations*, 23(4), pp.759–788.

Subgroups

- Involvement in pre-clinical research (design and delivery).
- Involvement in ethics.

Summary of the scoping review

3. Summary

There is a growing community of interest in public involvement with non-clinical research. This includes people and patients, research organisations and funders, researchers and practitioners. There is also a growing evidence base and guidance on how to plan and deliver public involvement with non-clinical research. In addition to the UK, lots of work is happening in Ireland and Canada.

Public Involvement with non-clinical research does have some unique, though not insurmountable, challenges. These include:

- Identifying public partners is trickier – unlike most clinical research, it isn't always obvious who the stakeholders are.
- The impact and/or direction of research is further away from application and may be unknown.
- For some of these areas, there are ethical, legal and social issues which (from our previous experience) can make researchers more fearful of involving people, and will certainly require great care in involvement practice to ensure no harm is done to public contributors.
- The non-clinical landscape is by its nature not as relatable to the day-to-day life experiences of patients and/or the public as clinical research. The context and environment in which the research takes place is quite different; and the content of what is being studied can be complex and detailed.

Through our scoping review we have identified and summarised a number of common features which are important for public involvement in non-clinical research.

The list below identifies enablers, benefits, impacts, barriers and challenges of public involvement. (It is worth noting that many of these are shared with public involvement with research more generally).

Enablers for public involvement

Funding & funders

- Public involvement as a requirement from funders of non-clinical research
- Support from funders and through funding

Team & Support

- Arrange the team structure to support public involvement.
- Plan for equitable division of responsibilities to reduce the burden on the project team and help partners feel more invested
- Support from a professional expert
- Provide competitive salaries for engagement and involvement practitioners
- Support of senior colleagues
- Support with logistics

Scoping review

3. Summary

Enablers for public involvement (continued)

Learning & Development

- Training/development at every career stage,
- Resources for researchers to overcome challenges
- Toolkits and standards
- Distribute learning materials before and after meetings
- Opportunities for researchers to practice in safe spaces – this can support communication and language, and overcome barriers around having difficult conversations

Strategy & Planning

- Supporting scientists to start involvement early / Develop patient engagement strategies ahead of time – this benefits involvement that shapes research priorities and is strategic/ will add most value
- Clarity of purpose of the involvement

Relationships with people and communities

- Building long term relationships is key – face to face activity can be beneficial although not essential
- Involving the 'right' people – based on interest, diverse lived experience, science backgrounds are not necessary
- Consider the needs of the community
- Partnering with external organisations that actively support patient engagement in non-clinical science research projects

Involvement practice

- Regular consultation and continuing conversations – learning together and building mutual understanding
- Creating a safe space where patient partners and researchers feel comfortable to collaborate

Communications including:

- Clarity and language
- Keeping PPI contributors informed
- Sharing examples of good practice

Scoping review

3. Summary

Benefits and impacts

Mutual learning

- including public partners' understanding and interest in basic science research, and researchers' understanding of the real-life priorities and impact of their work
- Improved skills and confidence in public involvement for all constituencies

Opportunities to build new knowledge, interests, and perspectives

- PI can inform and broaden perspectives and knowledge of researchers, raise questions that researchers may not have thought of and help them to think differently
- Involving a diverse patient partner group provides a greater understanding of diverse experiences

Improved quality and efficiency of research

- Public involvement informs the research question, study methodology, and future research direction by fostering important discussions
- Patient partners can play an important role in disseminating research findings

Other

- May increase trainee recruitment/retention, external collaboration, and recruitment
- Improves communication between the different stakeholder groups
- Improves patient/ public partner trust in the research community and strengthens the research through trust
- Encourages a sense of partnership (between patients and researchers)
- Creation of beneficial external partnerships
- Increases self-confidence and the impact of the patient voice
- Improves motivation for researchers
- Reassures researchers that what they are doing is of value
- Impacts on public/patient partners can include feelings:
 - of hope for their condition even if this may be in the distant future
 - that they are doing something useful
 - of being part of a wider community
- Impacts can be greater than originally envisaged

Scoping review

3. Summary

Barriers

- Structural barriers including time, funding and systems & processes
- Terminology
- Public partners identifying opportunities to get involved
- Researchers' fear of saying the wrong thing
- Researchers lacking knowledge and confidence in ethics
- Public partners' health
- Poor communications (from researchers)

Barriers most relevant to non-clinical research:

- Lack of researcher training opportunities to guide meaningful patient engagement in basic science research
- Researchers/practitioners lack of awareness of different approaches to non-clinical research
- The impact and/or direction of research is further away from application and may be unknown
- Defining the public stakeholders
- Public partners lack of experience of lab-based research

Challenges

- Research culture may not be conducive to involvement
- Lack of research experience, preparation, and clarity around expectations for public involvement
- Researchers concerns about how many people is enough
- Diversity of public partners
- Power imbalances between research community and public partners and practitioners
- Addressing the priorities of all team members can be difficult to achieve
- Researchers/practitioners' concerns around group dynamics or managing difficult situations
- Concerns about raising people's expectations regarding timelines of research into practice
- Measuring and reporting on impact – especially how to compile qualitative evidence across programmes/ organisations

Scoping review

4. References

4. References

The following is the long list of references from the scoping review. Further reading and a list of toolkits is also provided in Appendix 8.

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MRC Review of public involvement in research (2022)

Complete list of documents

Looking forward: Working with the Medical Research Council towards a public involvement strategy (Main report & Executive Summary)

Appendix 1 Methodology of the MRC public involvement review

Appendix 2 Landscape review of public involvement in non-clinical research

Appendix 3 Tweetchat #Involvement_Preclinical

Appendix 4 A patient's desktop review of public involvement at the MRC

Appendix 5 Examples of MRC public involvement

Appendix 6 Public involvement in research survey

Appendix 7 References and toolkits about public involvement in research

Please see full list of acknowledgements in Main report

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