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Animal Research Nexus

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Patient and Public Involvement and Engagement (PPIE) with Animal Research

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INTERIM REPORT FROM THE ANIMAL RESEARCH
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Executive Summary

Patient and Public Involvement and Engagement (PPIE) is increasingly embedded within healthcare research. PPIE seeks to enable patients and members of the public to apply their priorities to the development and delivery of health services and improve the quality and relevance of research by drawing on the lived expertise of individuals affected by the health conditions that research aims to benefit. These activities are varied. They range from the identification of research priorities and questions, the appraisal of study design, visits to research facilities, to the dissemination of research results. 'Lay people' can become involved at multiple points within the research pipeline and are increasingly encountering basic and preclinical research further 'upstream'. The movement of PPIE into basic and pre-clinical research raises new questions for practices of involvement and engagement, particularly, in emerging **interfaces between PPIE and animal research**.

We have been using qualitative research methods to trace the ways in which lay members and publics are encountering animals within biomedical research as part of a **Wellcome Trust Collaborative Award** (see [Annex](#)). We are seeking to understand how involvement and engagement activities can be organised in ways that are sensitive to the diverse experiences of lay members, researchers, and others involved, and open up authentic and meaningful conversations. This involves working with a range of different stakeholders: engaged and involved lay members, research funders and involvement professionals, and basic and translational researchers to progress conversations around PPIE with animal research. In this report we present our preliminary analysis and invite feedback around the themes, questions, and recommendations that have emerged since we commenced this work in autumn 2017.

Our initial analysis indicates that different groups approach and understand these encounters with animal research in different ways and that the motivations and expectations for involvement and engagement vary.

- Many **lay members** see value in opening up conversations about animal research. Their encounters can alleviate the anxieties and concerns lay members have about animal research by providing opportunities to learn more about how animals are used. Being part of decisions about research priorities and being able to ask questions about research practices is welcomed. However, many question how far they are listened to and for some being involved in research that uses animals is an additional ethical and emotional challenge that presents challenge within involvement.
- Many **funders and organisations** facilitating involvement and engagement believe lay members can, and should, be involved with all types of research, including animal research. However, there is also apprehension about how to organise PPIE around animal research, how to manage potential public and lay members concerns, and when and whether it can make a meaningful difference to research.

- 🍷 For **researchers** using animals, PPIE can be an opportunity to engage lay members' lived experience and expertise in research, to make research needs visible to researchers and colleagues, and help ensure research will be meaningful and beneficial to people affected. However, these conversations can be uncomfortable and there are challenges around how best to communicate and listen.

PPIE with animal research is an emerging area, informed by changing cultures of communication and openness around animal research, and the movement of PPIE practices into basic and preclinical research contexts. As PPIE practices are increasingly embedded in research funding and strategy, interfaces between lay members and publics with animal research are likely to become more common. Whilst many people find it challenging having conversations about animal research, there are also potential problems from not having these conversations for research transparency, authentic engagement, and research translation. Growing patient and public interfaces with animal research may also contribute to shaping cultures of care within the laboratory and conveying these cultures of care outside of them.

Existing practices of involvement and engagement do not map easily onto the opportunities and challenges presented by animal research and require flexibility in definition and implementation. Our research suggests lay members, involvement professionals, and researchers do see value in creative, comfortable, small-scale experiments that inform, engage, and involve lay members and publics in practices around animal research.

In our recommendations we suggest more meaningful and accessible PPIE around animal research can be supported through:

- 🍷 Creating appropriate **time, space, and resource** for patient and public involvement and engagement activities to be conducted within research practices and for meaningful relationships to be built.
- 🍷 Creating processes that **enable people to encounter animal research on their own terms** and to the extent to which they are comfortable. The opportunity to ask questions, receive **feedback**, and **opt-out** of certain aspects of research involvement is important.
- 🍷 **Connecting involvement and engagement** activities to empower lay members to have more confidence to be involved in conversations about animal research. Good involvement is informed by good engagement.
- 🍷 Recognising that the value of PPIE with animal research includes not only the potential delivery of better research, but also developing the confidence of lay members and widening their contribution to the **harm-benefit analysis** of research and the creation and communication of **cultures of care**.
- 🍷 Providing and sharing **training and resources for research staff** to identify the potential for meaningful PPIE with animal research. Case studies of good practice and innovation would raise awareness of the opportunities to inform research, but also the challenges and sensitivities that need to be navigated.

- 🌀 Generating and sharing **training and resources for lay members** to help them engage more fully with the topics and materials around animal research. Accessible information for lay members on current questions around animal use at different stages of research and the existing frameworks used to evaluate animal research (e.g. 3Rs, Harm-Benefit Analysis) would support genuine conversations. Lay members need to be well informed and given honest and realistic information in order to make meaningful contributions.

We hope this interim report will stimulate further conversations around PPIE with animal research. Understanding how lay people can contribute to biomedical research priorities and practices requires discussion and learning across different perspectives. In the next phase of our research we will consider how these future opportunities can be developed in collaboration with lay people, practitioners, and researchers.

- 🌀 We plan to convene a **stakeholder and scientist workshop** to discuss current challenges and future opportunities for PPIE with animal research.
- 🌀 We will seek to **identify and collate a series of case studies** highlighting opportunities for PPIE in animal research.
- 🌀 We plan to produce short **guidance around the training needs** that exist for lay members and researchers interested in PPIE and animal research.
- 🌀 We will produce a series of **academic outputs** on the topic of PPIE and animal research connecting our work to ongoing debates around public involvement, harm-benefit analysis, translational research practices, and cultures of care in biomedical research.

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1. Introduction

“There is a voice that’s often missing when we talk about research using animals. While those for and against such research debate the ethics and practicalities, the people animal research aims to help — patients — are rarely heard from.”

(Genetic Alliance UK, 2013)¹

1.1 Research context

This report reviews the different perspectives, challenges, and opportunities around the changing role of patient and public involvement and engagement (PPIE) with animal research. Using animals in research has been critical to the development of modern medicine, generating improvements in human and animal health. Recent developments towards widening involvement in research and increasing openness around animal research are generating new questions about how patients and publics might contribute to reshaping research practices and public conversations around animal research.

Research funders and engagement professionals are leading the rapid growth in new forms of PPIE across health research and clinical delivery. **Lay people and patients** are increasingly being asked to help shape the development of effective and ethical biomedical research at all of its stages, from improving proposals to the dissemination of findings. **Biomedical researchers** are increasingly expected to be open and transparent, to translate laboratory findings into new drugs and treatments for humans and animals, and to engage the publics and patients who stand to benefit from their research

However, PPIE in basic and animal research is less well established than in clinical or care research, and often seen as being less influential. As the Shared Learning Group on Involvement in Research² (2016) note *“much has been written about involving people in clinical, public health and social care research. Much less has been written about involving people in laboratory-based research”*.³

In addition, animal research remains a challenging topic for many in society and there are ongoing scientific debates about how further to reduce the harms to animals in research and realise the potential research benefits from animal research. Our work seeks to understand how lay people, funders, practitioners, and researchers can engage across their different perspectives and contribute meaningfully to these wider social and scientific conversations around animal research.

¹ <https://mrc.ukri.org/news/blog/introducing-patients-to-animal-research/>

² The Shared Learning Group on Involvement aims to encourage shared learning about service user and/or carer involvement between national voluntary sector organisations in the UK.

³ <http://slginvolvement.org.uk/wp-content/uploads/2016/09/Lab-based-research-FINAL-10-8-16-public.pdf>

1.2 Research terminology

We use the terminology of ***Patient and Public Involvement and Engagement (PPIE)*** to encompass the range of different ways in which patients and publics are now being involved in and engaging with research that involves animals.

The term PPIE is increasingly used in literature to account for the blurred boundaries between the identities of patients and publics, and the practices of involvement and engagement. Our research starts from an interest in the growth of involvement processes within basic and translational research. The majority of our interviewees, collaborating stakeholders, and the analysis in this report explores involvement practices. However, we have found that building positive involvement processes often also involves engagement, so we have adopted the term PPIE to encompass both where relevant.

We recognise acronyms can be a barrier to clear communication. We use the term here as it is inclusive of the range of definitions used by stakeholders in our research. It also does not impose distinctions that may be a barrier to learning across people and practices of involvement and engagement around animal research. PPIE also accounts for the complex geographies of these terminologies. What is referred to as ‘patient involvement’ in the UK is often referred to as ‘patient engagement’ elsewhere in Europe.

The category of ***patient*** is both complex and dynamic, in that all of us have been or will be patients at some time in our lives. The term ***public*** is similarly multifaceted, as it may refer to specific interested publics or ideas around the general public. We specifically use the term ***publics*** to emphasise the plurality of different preferences and views, rather than attempting to suggest there is a singular and static public opinion. Talking about ***patients and publics*** recognises we all have experiences around health that bring us into some kind of relationship with animal research as patients, potential patients, carers, family members, and members of society.

Many organisations have a specific term to refer to those people taking up invited involvement roles in research, such as volunteers, people affected by health conditions, or consumers. We use the phrase ***lay members*** to discuss the range of these more formal roles in our report. We refer to these as ‘members’ as we are primarily talking to those who already hold active roles within research projects and/or have taken on a formal role within research involvement networks.

The term ***lay*** means non-professional. In research, lay refers to people who are neither academic researchers nor health or social care professionals, not as a means of denoting a lack of skill or status, but recognising different forms of expertise and ways of relating to research. Within animal research, ‘lay member’ usually refers to the role of lay members within Animal Welfare and Ethical Review Bodies (AWERBs) in the UK, and similar committees elsewhere. However here, we use lay member in a much wider context, recognising the growing diversity of ways in which patients and publics are involved in making decisions about animal research (see, for example, Table 1, on page 12).

Involvement (or, patient and public involvement – PPI) is seen as carrying out research in active partnership with people affected by the research. It involves doing research ‘with’ people affected,

rather than ‘to’, ‘about’ or ‘for’ them. In involvement activities, lay members take on formal roles within research processes, drawing on their lived experiences to help prioritise research strategies, offer advice as members of a steering group, or comment on and develop research proposals.

Engagement (or, patient and public engagement – PPE) is the sharing of knowledge and information about research. Engagement can be targeted at specific groups, such as patient groups or students, or to the wider public through open days and science festivals.

We suggest the emerging processes of **involvement and engagement** around animal research are interconnected and related; good involvement often requires good engagement, and good engagement may build capacity for involvement. We include the diversity of encounters, events, and activities that comprise PPIE around animal research in our research. We are interested in all of the interactions that take place between different individuals within events to understand how they shape the exchange of experiences and expertise between people, and how they may be enhanced.

1.3 Research aims

This research is being carried out at the University of Exeter by Professor Gail Davies and Dr Rich Gorman as part of a larger **Wellcome Trust Collaborative Award on The Animal Research Nexus** (2017-2022). This programme of work seeks to understand how the connections between scientific practices and social processes around animal research are forged and transformed, with the aim of enhancing conversations between science, health, and animal welfare. There is more information on this collaborative project in the [annex](#) to this report.

Research at the University of Exeter is exploring the **changing opportunities for PPIE** in biomedical research and seeking to understand how lay involvement in biomedical research may contribute to generating productive dialogue around animal research. These conversations include societal debates about the acceptability of animal research in different contexts, as well as scientific debates around translational research, research quality and reproducibility, and animal welfare. We are tracing the ways in which patients and publics are encountering animal research to understand their experiences and how they might shape biomedical research practices and wider social relations around animal research. We use qualitative research methodologies (including interviewing key stakeholders, participating in events, and organising group discussions) to develop understandings of different people’s expectations and perspectives of encounters with animal research. Our research seeks to gather these different perspectives together to understand how involvement and engagement work, what they contribute to scientific and societal debates, and what might be done to organise activities that are valued by the lay members, researchers, and others involved.

We focus on the use of animals in **translational biomedical research**, which involves the use of animals in different stages of research and testing. **Translational research** aims to ‘translate’ findings from basic research (research that generates new knowledge of biological processes and potential drug targets) into new medical interventions with meaningful health outcomes. This is conventionally seen as starting with preliminary explorations of disease mechanisms in animal models, moving to

the identification and evaluation of potential drug targets in pre-clinical research, through to standardised safety and efficacy testing of drugs, with the aim of eventual using new drugs and treatments in human clinical practice. There are research choices and challenges of translating research at each stage. Failures to translate research are a recognised societal concern for those who stand to benefit from research and for those for whom the ethical acceptability of animal research depends on both reducing harms to animals used in research and realising the potential health benefits. Many of these are scientific and technical issues, but through PPIE there may also be the opportunity for lay members to learn more about how animal research is carried out, contribute to these wider societal debates, and potentially inform research decisions in ways that address these challenges to translation.

We are extremely grateful to everyone who has taken the time to share their thoughts and experiences with us so far and look forward to further interesting conversations about the potentials of PPIE with animal research. If you have any comments or questions about this report, including further recommendations, please get in contact with Dr Rich Gorman (r.gorman@exeter.ac.uk) or Professor Gail Davies (g.f.davies@exeter.ac.uk).

2. Research Methods

As social scientists, we use qualitative methodologies to understand the changing roles of PPIE with animal research. Qualitative social science research aims to shed light on how people understand, experience, and interpret different parts of their lives. Qualitative methods focus on generating understandings through communication, observation, and participation. Through these methods detailed and particularized descriptions of people's encounters can be produced that highlight the contextual and subjective aspects of different events – such as PPIE events and activities – and provide the basis for exploring how future activities might be enhanced.

2.1 Interviewing and learning from different stakeholders

Interviewing is one of the most commonly used research methods in the social sciences. Interviews enable researchers to learn from interviewees' perspectives, their situated and contextual experiences, and their attitudes and feelings about events. Interviewing involves conversations that follow a pre-prepared schedule of questions, with the flexibility to allow interviewees to pursue topics that are of interest and value to them and discuss what they view as important. Our research interviews explore the framing and institutional use of PPIE activities around animal research and develop an understanding of different people's expectations and experiences of these events.

We **selected interviewees** through mapping PPIE activities around animal research via policy review, media analysis, and a comprehensive web search for organisations that were facilitating some involvement and/or engagement with animal research. This revealed medical research charities who ran involvement networks and panels and individual research institutions hosting open days and events. When approached, many representatives from these organisations saw an interest and value in our research and agreed to share their thoughts and experiences with us.

We subsequently used '**snowball sampling**' (using one contact to help recruit another contact, who in turn can potentially put you in touch with another contact) to draw on stakeholders' own knowledge of the PPIE sector. Interviewees identified other key individuals and organisations to speak to about our research – for example, scientists who they had funded that did innovative involvement work around animal research. In addition, several medical research charities offered us the opportunity to survey their involvement networks and panels, inviting lay members active in research involvement to participate in a research interview.

These conversations lasted for around an hour and gave people an opportunity to discuss what they felt were the key features, challenges, and values of involvement and engagement activities within the context of animal research.

We have carried out interviews that included the view of 47 individuals to date. Of these:

- 🍷 **Twenty-one were with lay individuals** who have experience of taking part in a range of PPIE activities, including formal lay member panels and attending engagement days.
- 🍷 **Seventeen were with professionals involved in funding research or supporting research involvement and engagement** through roles on funding bodies, research support charities and/or medical research charities.
- 🍷 **Nine were with basic and translational research scientists** who had some experience of, or were seeking opportunities for, a level of PPIE in their research.

All of these conversations were recorded, with interviewee's consent, and transcribed to allow analysis by the research team. All respondents have been given pseudonyms.⁴ These interviews provide an opportunity to understand the priorities of key stakeholders and lay members involved in PPIE with animal research. They highlight key connections, themes, and questions, and help identify and address the challenges that exist as practices of involvement and engagement increasingly interface with animal research.

Our analysis of these interview transcripts is still at a preliminary stage. We share our initial thoughts, alongside quotes from contributors, in this report to help develop our analysis and build further conversations to enable more meaningful involvement and engagement around animal research.

As part of our commitment to working collaboratively with stakeholders, all contributors to this research were invited to comment on a preliminary draft of this report. The generous feedback, thoughts, and comments we received have helped refine our analysis and recommendations.

2.2 Participating in activities and events

Participant involvement is a qualitative research method in which a researcher takes part in the activities being studied to understand how such events are structured and listen to the perspectives of those taking part. In our research, this has involved **attending and participating in engagement events and 'patient' open days and tours** at animal research facilities. Informal conversations during events allow us to gain a better sense of why people choose to attend these events, what they expect, and what they find challenging. It also enables us to see the varied ways in which different organisations organise and frame their events, the labour and effort that goes into producing them, and the range of roles and expertise they involved.

We have also attended **'lay member facing' conferences and events** to learn more about the opportunities and challenges of PPIE as a whole. PPIE in animal research is part of a larger trend

⁴ As part of the overall Animal Research Nexus programme's pseudonym naming convention, interviewees in the 'Patient and Public Involvement and Engagement with Animal Research' strand of the project have been assigned pseudonyms beginning with R, S, T, or W.

towards openness and patient centricity. Understanding how these practices of involvement and engagement interface with animal research requires recognising challenges and movements within the sector at large.

Table 1 indicates the types of PPIE activities we have been engaging with, listing the aims of these events and the reflections on them by lay members in interviews. These reflections were often used to inform further interviews and will be explored in more detail in future analysis.

Table 1: Types of PPIE activities and lay member reflections

PPIE Activity	Lay Member Reflections
Attending engagement events and visiting laboratories to learn more about research into health condition	<p><i>“I was just kind of interested in seeing an animal lab. I’d never really thought about it much, but it seemed interesting. I don’t have much of a science background, but I think because of being involved in the [involvement network] side of things, I’ve tried to build up a bit more understanding of it.”</i></p> <p>Ruby (active in research involvement for over 3 years)</p>
Setting research priorities, agendas, and strategies	<p><i>“They have got a group together looking at their cancer research strategy for the university and they have patient involvement people on that. It’s looking at research strategy, which is good, having the public feed into that.”</i></p> <p>Tara (active in research involvement for over 3 years)</p>
Helping to develop research proposals	<p><i>“We can add value by looking at it through the eyes of people living with [condition]. Do we see it as a priority? How would that impact us?”</i></p> <p>Rachel (active in research involvement for over 5 years)</p>
Deciding what research to fund by reviewing, ranking, and scoring research proposals, making decisions about whether the research addresses important and relevant questions	<p><i>“I’m involved in reviewing applications. I need to have some understanding of exactly why the research is being undertaken, because unless I have confidence that there is some logic as to why the research is being undertaken – and that would include as to whether the right model is being used as well – otherwise the money you spend on such research projects is going to be wasted. My role is trying to help the [charity] make sure that every penny it spends on research is well spent. I don’t need to understand the full scientific reasons as to what this specific mouse model does, [...] just that the model being proposed is appropriate and that the science is robust.”</i></p> <p>Toby (active in research involvement for over 5 years)</p>

Shaping ongoing research through being involved in steering groups and visiting researchers and laboratories to help monitor the progression of projects

“More recently, I got involved in actually visiting and monitoring - or looking at - a piece of research that’s going on that involves flies and all sorts of things. [...] It’s fascinating and for me [...] there is nothing like going to a lab and talking to people and being able to ask the daft questions. So that then you feel like you’re hanging in there, you’ve got some basic understanding of what it is they’re doing and what they’re trying to achieve, and then I try and make those sorts of other connections between their science and my real experience.”

Rachel (active in research involvement for over 5 years)

Disseminating research findings and talking about research that has involved in the use of animals

“The other side of it is more the poster boy kind of side, for [condition] research, I think patient reps, we do a surprising amount of dissemination work”

Tristan (active in research involvement for over 3 years)

2.3 Organising workshops for discussion

Alongside interviews and participation, we organised and facilitated two workshops bringing together key stakeholders and lay members with an interest in developing new forms of communication and collaboration around animal research.

The first was a **stakeholder workshop for the whole Animal Research Nexus** project in June 2018, where we obtained feedback from our Programme Advisory Committee and others on our emerging research plans and themes⁵. This event included discussions around topics such as how harm-benefit analysis and cultures of care can form the basis for integrating new voices into animal research.

The second involved **lay members from across the biomedical research sector** in October 2018. This included lay members from different research committees, patient and health service user groups, patient involvement panels, and Animal Welfare and Ethical Review Boards (AWERBS). This aimed to provide a supportive forum for lay members to meet as a group and share experiences. We wanted to enable people to discuss the issues that concerned them, provide an opportunity to build dialogue across different perspectives, and explore the opportunities and challenges of discussing and shaping biomedical research. We offered workshop participants the chance to set their agenda for how such challenges might be addressed. The workshop was funded by the Wellcome Trust and facilitated by the independent facilitator Dr Jo Welsman.

⁵ For more information, see <https://www.animalresearchnexus.org/blogs/safe-space-talking-about-future-laboratory-animal-lives>

Thirteen people attended the workshop, including some who had already taken part in interviews. People's experiences of biomedical research came from involvement with AWERBS or membership of specific medical research charity's involvement networks (such as The Alzheimer's Society's Research Network or the National Cancer Research Institute's Clinical Studies Groups). Others were lay advisors within biomedical research centres or worked as independent lay representatives.

The workshop participants had a range of experiences of PPIE. Despite this diversity, attendees did recognise shared issues and core concerns, and valued the exchange. Their discussions included:

- 🍷 **Whether lay members had the confidence and power to effect change.** People's experiences of committees varied from feeling intimidated and reluctant to ask questions, to feeling able to influence decision making and being an equal partner.

Some attendees reported that the workshop had enabled them to feel more confident about being involved and asking questions in involvement processes. One commenter suggested that following the workshop, they aimed to be *'more vociferous in demanding proper lay explanations of the science proposed behind a line of research'*.

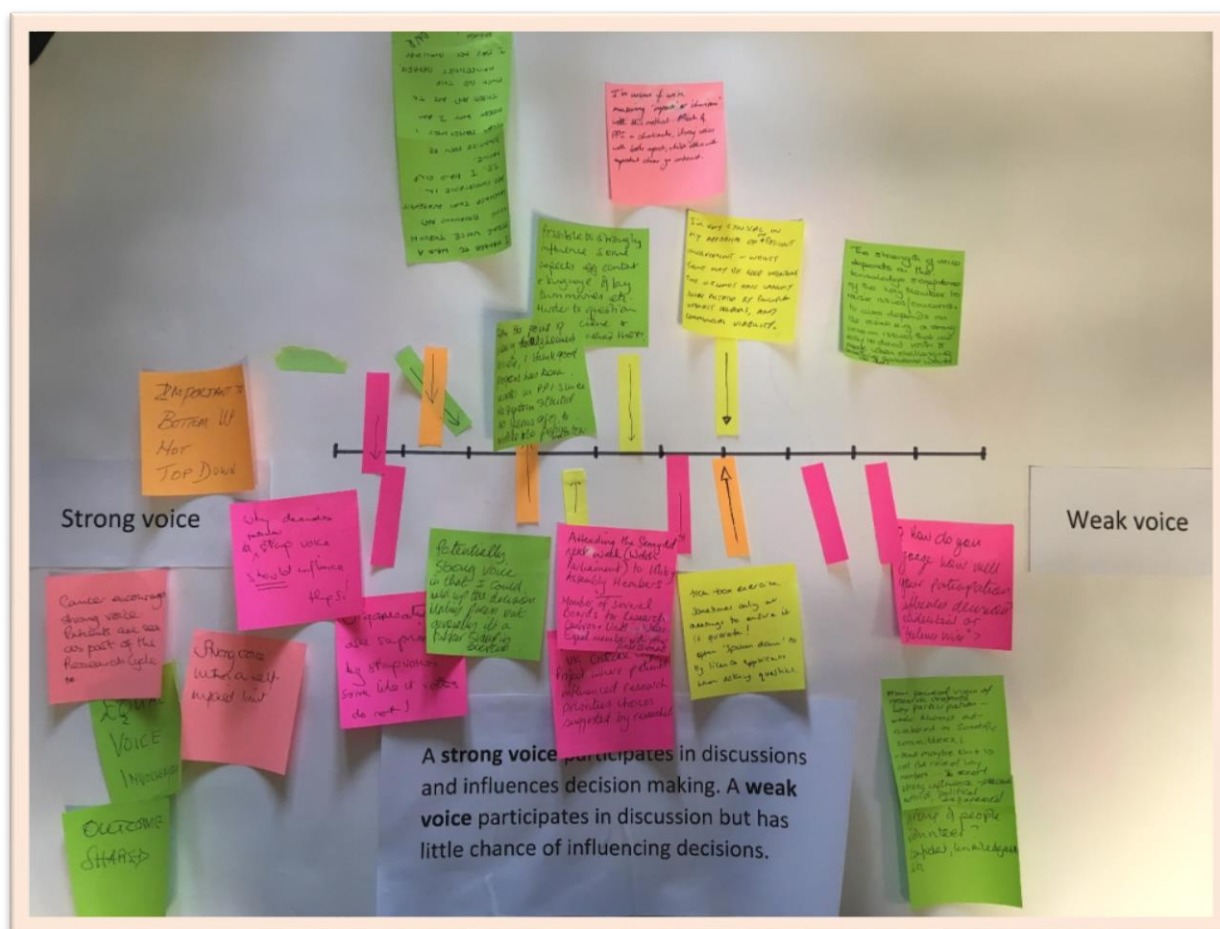
- 🍷 **The extent to which their involvement effected change within organisations.** Some lay members felt their participation was tokenistic and unlikely to change organisations, while others felt that any involvement was better than no lay member involvement, and small "nudges" would have a cumulative effect upon organisations.

Some reported the event had inspired them with confidence in processes of public involvement and reinforced the contribution that lay representation could make. Others found this aspect more challenging: *'I came away with a strong sense of how the bottom line of money, status and reputation [in science] has an overarching impact'*.

- 🍷 How far members of the group could **learn from each other across their experiences**, particularly around what it meant to be a single lay member on an expert committee and how to manage this role.

The workshop participants reported that drawing together a variety of lay members was useful in providing a unique space for sharing experiences. Attendees enjoyed working across their different groups and experiences and valued *'understanding how people from such diverse platforms have so much in common and how we can learn from each other'*.

Figure 1: Workshop participants record how far they feel they have a voice in decisions



A detailed report of the discussions that took place at this workshop can be found in our report 'Lay Members in Biomedical Research', available at: <https://animalresearchnexus.org/publications/lay-members-biomedical-research-report>

In identifying future priorities, workshop participants suggested we should run a similar event with scientists and research funders in the future. Attendees at the workshop wanted to know 'how their involvement has helped' and understand what 'lay' input meant for the organisations whose committees they sit on and the researchers whose work they commented on.

As part of continuing to develop conversations about PPIE and animal research, **we introduce the preliminary analysis from our research and invite feedback on the themes, issues and questions we identify**. In the rest of this report we map out the different expectations of what PPIE can, could, and should deliver as it increasingly moves into more 'upstream' into pre-clinical contexts and encounters animal research. We draw initial conclusions around the opportunities and challenges that are shared in order to identify preliminary recommendations and inform the next stage for our work.

3. Lay member and public perspectives


Explicit discussions about patient and public involvement and engagement (PPIE) with animal research are still relatively new. However, lay member involvement with animal research is already happening, often implicitly and in the margins of broader events and activities that aim to give lay members the opportunity to discuss and shape biomedical research. From the brief mention of a mouse model in a project proposal, to inviting lay members on a steering panel to visit an animal facility, lay members are learning more about how animals are involved in the research they are asked to review.

Many lay members see value in opening up these conversations, feel it is important to learn more about animal research, and value being able to make more informed decisions about whether they feel research is worthwhile. For others, being involved in research that uses animals is an additional ethical and emotional challenge that hinders their involvement. Lay members want to support and contribute to research, and many do not want to be excluded from the details of discussions that involve animal research as it may affect the input that they provide. Additional sensitivity, training, and resource is needed to enable productive and meaningful conversations with those who want to know more, and provide alternative routes through PPIE for those who do not.

3.1 Learning is empowering for some, but not for all

Learning more about the use of animals in biomedical research was cited as a positive experience for many of the lay members who attended engagement events themed around animal research. For those who did want to learn more, it was felt to be empowering for their understanding of their health conditions, their views around animal research, their involvement in processes of research evaluation, and their contributions to supporting researchers. However, not everyone wanted to learn more about the use of animals in research and it is important to recognise and respect these views, especially as the potential to take part in PPIE events may come at a time when their personal understandings of health and identity are changing.

Taking part in PPIE events did alleviate concerns and worries that some people had about being reliant on research that involves the use of animals. Lay members approached these events with some apprehension, but witnessing the care deployed for animals allowed lay members to develop confidence in advocating for the funding of further biomedical research and being involved in wider conversations that talk about animal care to those outside facilities.

 *“In a way, it put my mind at rest because you don't know what to expect until you go there. You just can't, because you've not been in that environment. You think it's going to be worse than it actually is.”*

Tessa (engagement event participant)

🍌 *“For the people who don't know a lot about labs, they really enjoy that because it's a sort of new world to them. It's a good thing to do, because a lot of members of the public are interested in what clinical research is about and it's part of this openness thing isn't it. If you let people into the labs, then they can see you're not trying to hide things.”*

Tara (active in research involvement for over 3 years)

The lack of past openness around animal research means few people had access to resources that prepared them for these encounters. There are now more ways for people to explore what an animal research facility looks like and what research might involve.⁶ However, histories of secrecy around animal research fuel anxiety, which might be acutely felt when suddenly affected by a health disorder, unless lay members had past experiences.

🍌 *“I'm quite glad that I've worked in them [animal research facilities] before so I know what to expect, I think if I hadn't, I think I would have found it a lot more difficult. [...] I may find it very difficult, when it's suddenly you that's affected by something, it does change your view on quite a few things.”*

Tabitha (active in research involvement for over 5 years)

For other people, learning more about research led to an interest in exploring opportunities for involvement. Developing relationships with researchers and becoming more involved was felt to be empowering personally and empowering for the researcher too. Good involvement often starts with good engagement:

🍌 *“Not only do we have a voice, but it also gives [a researcher] leverage in relation to his proposals. When he writes to a funding body, he can say he's spoken to people. He's not dealing with it in an abstract fashion, he's spoken to people and got their input and that, I'm sure, gives him more weight with his scientific proposals for research.”*

Tim (engagement event participant)

For yet others who are actively involved in biomedical research, research is research. Having animals involved in a piece of research does not change how they engage with research, or how they approach the tasks and activities that make up their involvement with research:

🍌 *“[There's] nothing specific about animals any more than there's anything specific to electron microscopes or whatever. [...] I would look holistically at an application or the lay summary and try to see whether it has maximum potential benefit to society and to the patient, that it is readable by the public where it has to be, and should it be funded?”*

Raymond (active in research involvement for over 3 years)

Some of the lay members active in research involvement would prefer to know less about animal research. They are not opposed to animal research, but they do not want to know the details. They feel comfortable in leaving questions around animal research to others, preferring to focus on the benefit, purpose, and relevance of the research, rather than the scientific methods. PPIE with animal

⁶ <http://www.labanimaltour.org/>

research involves a level of emotional labour on the part of lay members, in terms of accepting, justifying, and rationalising their engagements with research, treatments, and fundraising.

🍷 *“I’d rather just hand the unpleasantness over to them [scientists] and let them get on with it. I don’t really want to know. I know they use mice and I know they probably do some horrible things to them. But I actually don’t need to know this. I wouldn’t want to stop it.”*

Teresa (active in research involvement for over a year)

Indeed, the specific subject of animal research was, for a very few lay members, an area where asking for their involvement, or organising an engagement event, did go ‘too far’.

🍷 *“I did look at one application recently who said, ‘We’re going to have a meet the animal session’ and I thought ‘No, I really don’t want to meet the animals’. I like to know that they’re happy and content, but I don’t want to look at them and think, ‘what’s going to happen to you tomorrow?’ That went too far the other way.”*

Rhoda (active in research involvement for over 3 years)

It is important to recognise that not everyone wants to (or has the capacity to) become involved or engaged with animal research. However, there are significant number who do want to engage and feel it can help empower them, their decisions, and the research.

3.2 Conducting ethical evaluations is challenging

The lay members we spoke to often talked about the personal ethical frameworks they applied to make sense of the research involving animals they were asked to review. Many people do feel their involvement in animal research brings complex ethical responsibilities in making decisions about animal lives. They draw on a diversity of personal ethical perspectives to make sense of this.

Some address these questions through religion and may seek external advice on this point.

🍷 *“With the transgenic mice, I was a little bit apprehensive about it because I am a [member of a particular religion]. One of our tenets is not to kill any living being, so I in fact, consulted with my meditation teacher about whether I might be committing murder or committing the killing of the drosophila or the rats by participating in the monitoring – even though I’m not directly involved in the scientific part of it.”*

Win (active in research involvement for over 10 years)

Other times lay members talk about how hard it is to work within the way they are asked to score research proposals in a manner that both recognises the potential value of research and takes into account the ethical issues around harms to animals. We found some lay members in effect carrying out an informal harm-benefit analysis of animal research. They wanted assurance that the harms are being minimised and that benefits to human health will be realised before they are confident in providing a score for applications.

This meant many lay members wanted more detail and explanation included in the summaries and proposals that they read and comment on.

🍌 *“I do like to know the detail. I really want to know that they’re being treated humanely and that any suffering is minimised, and I do want to know that. I don’t want to have my brain working overtime thinking I’ve just given something a high score for research and I don’t understand what the animals have to go through. [...] When I review the applications, I’m not scoring them highly and I actually left a comment to say, ‘You might want to ignore my scores because I’m scoring it in the mid-range because I’m not convinced that whatever they find will be of real use’. I know every time you do something, you learn something, but you shouldn’t be using animals just for the sake of learning.”*

Tabitha (active in research involvement for over 5 years)

Not having this information caused anxiety to lay members about the research they might be supporting and how research organisations would make sense of their input. This lack of knowledge and the lack of a supportive space to talk about potentially difficult issues like animal research can generate anxieties, which in turn shapes how lay members approach their reviewing work and produces additional emotional burdens and stresses. There are opportunities to think about the impacts of being involved in this type of research, and the ethics of inculcating responsibilities and decisions amongst lay members.

🍌 *“But gosh, you know, if an animal did suffer, I don’t know how I would evaluate that application; if I knew an animal was going to suffer. [...] I think it would be good if we had more of these conversations [...] reducing that anxiety would be a huge help to me personally and reducing the guilt. There’s this dual thing going on, I want a cure to be found, I don’t like seeing people suffering either, but you just don’t want something to have to die for that to happen.”*

Tabitha (active in research involvement for over 5 years)

Lay members are often unsure what questions they were being asked to answer (ethical or practical), what they are evaluating (harms or benefits), and who they are speaking for (patients, publics, or animals). Some felt that their involvement in research brought with it specific duties and responsibilities to animals, conceptualising their role as one with a duty of care to animals.

🍌 *“That is a part of our briefing, that when there is an animal testing involved that we’ve also got to look into the welfare of the animals during the duration of the research.”*

Win (active in research involvement for over 10 years)

Lay members take the ethical responsibilities they feel they have very seriously and feel these are not always recognised and supported in the materials and processes that are provided for them.

3.3 Opportunities to support research are valued

Despite these challenges, many lay members see considerable value in using what they learn from their involvement to support research and publicly endorse animal research to others, particularly through talking about the regulation of animal research and focus on animal welfare in the UK.

- 🍷 *“I’ve been able to disseminate some of the knowledge, for example, when it comes to the use of animal testing. I’ve been able to explain and talk about the control systems in place and the ethics, the most robust in the world. If anybody has any concerns, I am able to communicate that to the families and carers I know.”*

Toby (active in research involvement for over 5 years)

Others saw themselves as having a role to play in advocating for high quality research, of whichever sort, whether this was an uptake of alternative methods to *in vivo* research, or the use of animal models when appropriate.

- 🍷 *“So it’s about supporting research into alternative methods [...] but also where it’s necessary to have animal models, because of the similarities to human tissue, they need to test that substance for how humans might benefit.”*

Tiffany (involved in research for over 5 years)

Lay members did frequently note a disconnection between lab-based pre-clinical researchers and people affected by different health conditions. These lay members saw PPIE as having a crucial role to play in supporting research, through being a source of interest and inspiration to basic researchers.

- 🍷 *“I think that then helps us to be a resource for the researcher. It gives them automatically people with a real interest and experience of the condition that they’re researching. I think for them, that lifts it above the Petri dish, that what they’re doing is for real people.”*

Rachel (active in research involvement for over 5 years)

Others were more cautious about this disconnection, wanting more information and potentially challenging how research priorities were shaped around the translation of research into a clinical context. This was not about how to balance the harms and benefits of animal research, but about which research pathways were going to be best placed to translate into deliverable patient-centric benefits more effectively and efficiently.

- 🍷 *“I would probably say I’m very pro-animal research and I think it’s a good thing. But given my situation, I’m actually more interested in human research on my condition because they’re a bit further down the line”*


Ruby (active in research involvement for over 3 years)

- 🍷 *“The kind of things that interest me is doing things in mice isn’t always helpful because as we know, the mice model doesn’t necessarily work on humans”*

Tracy (active in research involvement for over a year)

Finally, lay members recognised that they had a potential public role in making a link to wider societal debates around animal research. Many felt adding the voices of lay members to public debate could be an important method of advocating for research, both around biomedical research and around animal welfare.

However, there were still concerns that the potential tension of speaking both for research and animal welfare carried the potential to disrupt research. So long as public debates over animal research are strongly structured around pro or anti research positions, there are lingering concerns about lay involvement strengthening one side of the argument or the other, rather than trying to understand how to support both good research and good welfare.

 *“It is a contentious subject and some people feel very, very on the side of the animal. It would matter who you had working with the researchers. It’s dealing with a serious subject and acknowledging that. [...] I think if you had so much argument going on, if somebody disagreed so vehemently, you would get nowhere. It wouldn’t help the research, it wouldn’t help them, it wouldn’t help the researchers; it would be unhelpful.”*

Thelma (active in research involvement for over three years)

In the next section we review how the expectations, experiences, opportunities, and anxieties of lay members are reflected in the ways in which professional engagement experts and biomedical research seek to engage them in their work.

4. Funder, Charity and Researcher Perspectives


Funder organisations increasingly require the involvement of lay members in decision-making and public engagement around the research that they fund. There is general support by those promoting patient and public involvement and engagement (PPIE) that lay members can and should be involved with all types of research, including animal research. However, there are also concerns about how PPIE in animal research might be facilitated in ways that are accessible to lay contributors, do not add to anxieties around animal research, and might make a meaningful difference to research practices. More case studies are needed to enable organisations to demonstrate how involvement at earlier stages of research can be productive for everyone involved in the conversations.

Responding to these imperatives, researchers who use animals in their work are increasingly initiating conversations with lay members and patient groups. These new conversations are often hesitant and awkward, and there are still questions around how to communicate about animal research and how to listen to the points that lay members want to raise. Yet these dialogues have the potential to be intellectually valuable and emotionally important for all those involved in animal research. They may lead to new opportunities for identifying routes to translation, redefining research agendas, and perhaps even refining animal models.

4.1 Funders are creating spaces for PPIE with animal research

Our research indicates that many research funders and involvement professionals have strongly held beliefs in the potential of meaningfully embedding PPIE in all of the work that they do, including with animal research. However, they recognise challenges around PPIE in research that is further upstream and involves animals.


This belief originates from the desire to generate opportunities for listening to the voices of people affected by different health conditions and create space for their inclusion in conversations around research. Partly, this comes from recognising that patients' voices and opinions have not always been included or involved in discussions about animal research and that their involvement might help researchers address the right needs and use the right models for patients. At the same time, they recognised there was more work needed to provide the evidence that would enable them to translate these beliefs into the most meaningful form of PPIE.

 *“Patients should be and can be involved throughout. If it’s a piece of clinical research that’s been developed from animals, that hasn’t addressed the right need or used the right model, then obviously your clinical research will be affected. [...] I think in the earlier stuff, at the basic end, we’re starting, but we’re still finding our way a little bit, and still trying to figure out what will be useful and meaningful. The last thing you want to do is make it a tokenistic*


gesture and put a patient on a committee, ask them to review a piece of animal research that you've not really thought about why you want them to review."

Sean (Research Involvement Professional, Small Research Support Charity⁷)

Medical research charities acknowledge they are already organising PPIE processes in which lay members are encountering animal research. Many express concerns and uncertainties around not knowing how people were engaging with the animal research they encountered in these activities. Funders also recognised that they could be creating situations where their lay member volunteers do not feel comfortable.


 *"The way that we support things is often the researchers and people affected by [condition], we pair them up. So there may have been conversations around [animal research] that we're not aware of."*

Sabrina (Research Involvement Professional, Large Medical Research Charity)

 *"We have previously had people who don't feel comfortable reviewing animal research papers. [...] Sometimes because we don't ask people to give a comment in their reviews, it's difficult to know whether they are reviewing them high or low because they're animal research."*

Stephen (Research Involvement Professional, Large Medical Research Charity)

Other had started to have these conversations as their involvement of lay members in setting research agendas had led to the organisation beginning to fund more animal research to meet lay priorities. This introduces potential tensions with other areas of organisational activities, such as fundraising and communication. There are also questions about ensuring lay members have access to appropriate information and are supported in making a harm-benefit evaluation if they want.

 *"Our [lay members] were integral in defining the calls and setting the research questions. And that's very interesting actually, when it comes to animal research because clearly research into pain using animal models is research which necessarily causes pain in animals. So that's kind of thrown up a lot of questions for us about how we communicate that."*

Tom (Research Involvement Professional, Medium Medical Research Charity)

The concerns expressed here do echo comments made by lay members in the previous section. Funders are uncertain about lay member views when encountering animal research. Our research does suggest lay members are influenced in the information they want and the processes they use to review research when they encounter animal research. This highlights the need for more conversations and open discussions about the interfaces between PPIE and animal research.

There are also many people working within medical research charities and funder organisations who felt there was considerable potential in developing these conversations around research advocacy and translational research, again in ways that mirror lay member perspectives.

⁷ These are approximate categorisations, based on number of employees (1-50: small; 50-200: medium; > 200 large).

They also recognise that animal research has been dominated by strong ‘pro’ and ‘anti’ arguments. Allowing space for patients – the beneficiaries of research – to make meaningful contributions to decisions about animal research was felt by research involvement professionals to have the potential to widen the voices in this debate and open up more productive conversations.

🍌 *“Then you’ve got the people who are likely to be beneficiaries of this sort of research and their perspective, I don’t always think you hear from them. You might hear from the researchers. Or hear from people that are saying, “No, you should never use animals”. And, if actually those are the people with [health condition], we need to hear what they’ve got to say. But also for me, in my naivety maybe, I think it tempers the conversation because you’re trying to allow different people to have a voice, for it to be not dominated by researchers or dominated by any one voice.”*

Sally (Research Involvement Professional, University Sector)

There was also hope that further development of methods of PPIE might contribute to addressing challenges and gaps in translating research into clinical benefit that medical research charities were experiencing as a challenge in their own work.

🍌 *“That translation place is so obvious I don’t know why people haven’t landed on it earlier. Especially in an environment where they have to demonstrate translation now of basic research, I think to be able to do that, it’s really meaningful and actually very compelling on both sides. So that’s something that I am encouraging, when basic researchers come to us and have animal models, and don’t know where to go, that’s what I generally encourage people to do and think about. I like that gap, I like filling that gap with PPI.”*

Tom (Research Involvement Professional, Medium Medical Research Charity)

However, despite widespread beliefs about the rights of people affected by health disorders to have a say about research and the potential value they see in PPIE around animal research, many organisations are still uncertain about the practical value and processes of doing this. There is currently a lack of evidence around what works, which means there are still uncertainties about what will be useful and meaningful PPIE.

🍌 *“I think it’s a little less clear when it comes to animal research, what role [PPI group members] can play, the value of the contribution they can make and what that contribution would look like. “*

Rosalyn (Research Involvement Professional, Small Medical Research Charity)

Organisations suggest this lack of evidence leads to resistance from researchers about embedding involvement at earlier stage of research, as they cannot answer questions about when to use involvement processes or provide evidence of what methods have demonstrable impacts and benefits.

🍌 *“I think something that really we do get challenged on is the difficulties, or perceived difficulties, of involving patients and the public in basic research. It’s very easy to see the benefit of asking somebody how you design your clinical trial, but it’s much harder for*

researchers to then talk about, or think about, understanding how they might use patient and public insight in basic research”


Shirley (Research Involvement Professional, Large Medical Research Charity)

4.2 Biomedical researchers are seeking evidence

For researchers, PPIE can be a useful opportunity to draw on lay members’ lived experience and expertise to ensure research will be beneficial to people affected by specific health disorders. However, researchers who had experimented with PPI around animal research found these conversations could be difficult at times. There are also challenges around embedding mechanisms for PPIE when there is little evidence around what works best and when researchers are already under pressures of time and resources. Although many pre-clinical researchers we spoke to had been involved in tentative experiments with PPIE and animal research, many were still speculating on the challenges and opportunities produced by incorporating PPIE in their work.

Many researchers we spoke to saw value in involving lay members in a dialogue about research, whatever the stage, noting that lay members could generate useful new insights whether through informal conversations or more formal involvement processes. Lay input was valued as an effective and genuine way of making a contribution to the research, from promoting research to the general public through to more detailed questions about research techniques. However, researchers found some forms of input easier to incorporate than others.

For some researchers, embedding PPIE in animal research was an important part of opening up new conversations about the use of animals in science. A particular focus was on the importance of lay members being able to contribute to wider public discussions and help develop societal understandings of animal research.

 *“With the focus being on animal research, I think that’s actually an area where having patients that have had that close involvement with scientific researchers can then really make a big difference to the wider public knowledge and engagement with science in the area of animal research. It can be quite an emotive subject and so if you’re having a wider public discussion about it, having some people who are affected by a particular healthcare condition and have had close involvement with scientists in the area of animal research, can actually bring quite a lot to that discussion.”*

Scarlett (Biomedical Researcher, University Sector)

However, similar to the research involvement professionals interviewed, some researchers struggled to identify how involving lay members might influence their work, because of the pre-clinical context.

🍌 *“It’s not that I’m against talking to them. But fundamentally, because my research is at quite a basic level, it’s not going to change the things that I want to do. It’s just not, because I’m still going to want to look at the parts of the brain that I want to look at and I’m going to look at the sort of curiosity driven science that I want to do.”*

Sophia (Biomedical Researcher, University Sector)

Some scientists even expressed a concern that the movement of PPIE into pre-clinical research could result in a de-funding of basic research:

🍌 *“I think people [lay members of medical research charities] want to know where their money is being spent. They want to have an informed say in making decisions about the direction of the research and where the money is being spent. I think the risk is that [basic research] gets side-lined out of the science. In my experience, what we’re seeing at the moment is in the charity sector it being much harder to get basic research funded. What’s more likely to be funded is patient facing research, because they understand it better and they’re having a much bigger say in the way its funding is being directed. And I think that’s problematic.”*

Sian (Biomedical Researcher, University Sector)

However, other researchers valued lay member input and said it had helped understand how their existing research could be channelled into new possibilities for translational research in ways that enhanced the potential for benefit to patients.

🍌 *“It was a positive experience and I changed the plan and the dissemination accordingly. We were encouraged to take our research to drug companies and other investors who help bring related innovations to market because they [lay members] wanted to see those translated into new therapies as soon as possible. I took that advice to heart and I’ve now engaged several commercial entities involved in drug discovery, so it was useful.”*

Robert (Biomedical Researcher, University Sector)

Realising this value for researchers depends on recognising opportunities and being open to input from lay members when there are genuinely decisions to be made, including around the choice of further research using animal models or the use of alternatives. Good involvement may flow from good engagement, but here there may be a difference between the two that resides in the capacity of the researcher to act on the information that lay members provide. There is the suggestion that researchers, who may be increasingly happy to talk about animal research on the one hand, on the other are not yet ready to change their research based on the conversations that result.

🍌 *“I know colleagues that do an awful lot of animal research and are really great about being open to telling people what they’re doing and why they’re doing it. But I’m not convinced at the moment that they’ve made that shift to being prepared to make any changes to their experiments based upon their conversations with people affected by those conditions.”*


Scarlett (Biomedical Researcher, University Sector)

There are asymmetries of expertise upstream in research, which the fact that animals are being used make more difficult to address. The boundaries between involvement and engagement blur again for lay members; with more information and engagement they may be able to offer more involvement.

This is resource intensive. For some researchers, these are steps worth taking, but for others they are not.


Even if clear opportunities for listening can be identified, the interface between animal research and PPIE can be a source of anxiety for scientists as much as it is for lay members, and there are clear challenges for funders and research involvement professionals in alleviating these concerns. It can be difficult to create a space to talk about animal research within basic and preclinical research. Researchers may have questions they want to take to lay members, including how to select or improve animal models so they represent the most meaningful aspects of people's health concerns. However, finding ways to ask these questions is hard without clear evidence around what works.

Some of those who have experimented with these methods report lay people did not feel comfortable or feel like they had enough knowledge to talk about it.


 *“They [lay members] didn’t really feel comfortable talking or giving any kind of feedback on the animal research at all. When we asked them about how they felt about the animal model, the conversation was very restricted and very limited. They said, ‘We just don’t feel able to comment on this’. They felt uncomfortable, felt they didn’t have enough knowledge to talk about it. They didn’t think they had a valid opinion and they didn’t really want to have an opinion on it.”*

Sian (Biomedical Researcher, University Sector)

However, for most of the research we spoke to, there are hopes that involving, and listening to, lay members might enable conversations that helped to address the ongoing challenges of translating research from pre-clinical to clinical contexts. There are expectations that lay members' voices could help to identify the most effective routes to translation, define research priorities, inform research protocols, and perhaps refine animal models.

 *“What PPI could do, I think, is help to reverse the problem that the failure to translate has been such a catastrophe for the industry.”*

Sandra (Biomedical Researcher, University Sector)

 *“I think patients actually could really have quite a big and important role, in what are the things which should be assessed in the animal models that then hopefully would translate better to patients.”*

Scarlett (Biomedical Researcher, University Sector)

For some translational scientists, there was something quite specific and valuable in the interface between PPIE and animal research. For them, involvement was not a matter of simply adopting and applying a practice from clinical research, but rather, an innovative opportunity to conduct research in a way that might open new translational pathways, through informing research practices and building wider collaborative networks with industry and patient groups.

4.3 Summarising issues across perspectives

Whilst there are complex and diverse interpretations operating in the interface between PPIE and animal research, there are certain values and experiences that all groups seem to share around these encounters. Our review of the different perspectives across lay members, funders, involvement professional, and researchers indicates there are opportunities for all groups, but also complexities that have be considered. We summarise these here before exploring the prospects for generating future conversations in the next section.

Opportunities

- ❖ PPIE and animal research can be a positive experience for **lay members**, alleviating anxieties and concerns they have about animal research by providing opportunities to learn more and be actively involved in influencing and shaping research practices.
- ❖ PPIE and animal research can be beneficial for **organisations** that fund research and support PPIE by enabling patient centricity and patient voice to be embedded at all stages of research.
- ❖ PPIE and animal research can be useful for **researchers** as it provides the opportunity to draw on lay members' lived experience and expertise to help ensure research will be meaningfully beneficial to people affected.

Complexities

- ❖ PPIE and animal research is complex for **lay members** who both have their own concerns and interests and are being positioned by others as speaking for patients in general, for research in public, and sometimes for animals too. They may struggle to resolve these tensions in private.
- ❖ PPIE and animal research is complex for **organisations** as there is currently a lack of evidence around what works, and impacts may be less tangible, including supporting cultures of care, assuaging lay member anxiety, and building capacity for future involvement.
- ❖ PPIE and animal research is challenging for **researchers** who are not used to talking about animal research. While there are now resources for helping researchers talk about animal research at engagement events, there are still gaps around how to involve lay people in a comfortable and genuine dialogue around upstream research choices.

5. Furthering the potential of PPIE with animal research


PPIE around animal research is an emerging conversation informed by changing cultures of communication and openness around animal research and the movement of PPIE practices into preclinical contexts. It is also challenging as many people do have concerns around how to stage conversations about animal research. Our research has indicated that many of these concerns are common across lay members, funders, engagement professionals, and researchers. We suggest there is value in developing these conversations openly and that not having these conversations may give rise to anxieties and misunderstandings.


Overall, most lay members, research involvement professionals, and researchers see value in creative, comfortable, small-scale experiments that inform, engage, and involve lay members and publics in practices around animal research. This changing patient and public interface with animal research has the potential to shape public debate around animal research, affect cultures of care within and outside of the laboratory, and inform the priorities and practices of translational research. However, it is important to ensure involvement and engagement practices are not obligatory for all lay members.

As PPIE with animal research is only now emerging as a focus, there are challenges around evaluating evidence from isolated experiments. The activities and exchanges that are valued do not fall neatly into existing typologies of patient and public involvement and engagement. Patients and publics may only encounter animal research when changes in their health bring them into contact with previously unseen research contexts, meaning that for them involvement and engagement processes are closely linked. However, these activities are taking place in a research landscape in which funders and researchers are pressurised for time and resources, leaving less scope for developing PPIE that is not clearly evidenced and may not have tangible short term outcomes. This section looks across the different groups to identify ways of realising the potential of these conversations in the future.

5.1 Recognising the value of conversations

The lay members, funders, involvement professionals, and researchers we spoke to were recruited because of their connection to PPIE, so not surprisingly there was a common view that furthering PPIE around animal research was valuable. There was a shared recognition that these activities could be challenging and even awkward, but everyone had found their personal conversations rewarding.

 *“I really enjoy getting out and meeting people. It’s like a network [...] and I like to feel useful, I feel as though I’m doing something really useful and contributing, as well as enjoying it.”*
Tara (active in research involvement for over 3 years)

 *“It’s not just about an individual review of a piece of research. It may be involving patients in your strategy, it may be asking patients “What do you want?”, “What should our strategy be*

for the next five years?”, “What are the most pressing issues?” [...] that kind of thing, where you get the really valuable questions that can help a funder narrow down into some really niche areas that really matter.”

Sean (Research Involvement Professional, Small Research Support Charity)

🍷 *“Talking to that sort of an audience [lay members] is quite encouraging and certainly gives a sense of real value. It's very rewarding, and for that reason I'd like to further it.”*

Roy (Biomedical Researcher, University Sector)

Whilst a lot of effort often goes into defining ‘involvement’, and differentiating it from ‘engagement’, these overarching frameworks seemed less important to everyone involved when reflecting on their exchanges. Lay members were interested in having authentic conversations and developing relationships that enabled dialogue on equal terms. Research involvement professionals and researchers also recognise this and when talking about the activities they have organised, focus on trying to create a genuine dialogue within a conversation, whether this is construed as engagement or involvement.

🍷 *“I think relationships are quite important in this. You need to be able to say things honestly from the patient side of things, and you hope that the researchers will listen and think about why it's being said.”*

Thelma (active in research involvement for over three years)

🍷 *“I guess it's around how we create an environment where people can come together and communicate on equal terms. [...] That was partly why I did the agenda setting, trying to create a knowledge space where people could come together and have a conversation on more equal terms.”*


Sally (Research Involvement Professional, University Sector)

🍷 *“I really try to use it to open a dialogue and a conversation with that group. [...] I've found, from a basic research point of view, that having that first interaction about setting the scene, so they get to know where I'm coming from, what type of thing I'm doing, and can grasp some understanding of the biology that I'm talking about. I've found that subsequently, if I go back and have that dialogue and that two-way conversation - which will be more classed as involvement - then actually both of us get a lot more out of it.”*

Scarlett (Biomedical Researcher, University Sector)


Good involvement often starts with good engagement, particularly within basic and translational research. People need to feel empowered to have the confidence to be involved in conversations. Engagement events that produce curiosity and understanding can lead to useful dialogues and conversations between lay members and scientists about research. Individuals with responsibilities for both involvement and engagement in organisations need to work together to realise these opportunities. It will also be vital to involve organisational communications teams in developing and supporting a more open and two-way dialogue between PPIE and animal research.

These conversations were also seen as valuable as they developed new connections and relationships, bringing previously disparate stakeholders together in beneficial ways. PPIE can impact on the researchers and wider research teams, including animal technicians, as much as on the research itself. Animal technicians and technologists play a vital role in supporting animal care and use, which results in them doing a lot of the emotional work around animal research. They also have the potential to benefit from the opportunity to engage with the people for whom the research is being carried out, though this needs to be organised so animal technicians are not the ones taking on responsibilities for both caring for animals and caring for patients.

 *“I think to take it to the animals’ issues specifically, for the animal techs, it is hugely important. It gives them a real sense of place and a real sense of value to have encounters with patients. The techs tend to feel very disconnected, they’re looking after animals, that’s so far apart from what’s happening in this disease condition. They really get a sense of job satisfaction and a sense of value in feeling that they are part of a scientific process that is doing something good. It’s very easy for them to feel maligned and like their ethic is being eroded because of the job that they do. I think that contact with patients actually really helps to give them some perspective of where their work fits into research because they see that endpoint.”*

Ruth (Research Engagement Professional, Small Research Support Organisation)


Involving early career researchers in these activities can also enhance their understanding of the context and importance of their work and offer assurance to patient and public communities that there are ongoing efforts to address pressing health issues.

 *“It’s brilliant for the [early career research staff] to meet people with the disease and talk about their disease, to really bring home the context and the importance of the work. But I also saw that some positive feeling was generated from these people seeing the next generation. They saw that an investment was being made in these young people and they would work in this field for the benefit of [the condition], potentially for their whole careers. It gave hope of continuity in research. [The condition] is not being forgotten about.”*

Robert (Biomedical Researcher, University Sector)

The opportunity for new and open discussions about a topic that has previously been viewed as too controversial, can remind scientists and technicians why they do their (often emotionally challenging) work, and remind people affected by health conditions that there is careful work is going on.

However, as above, it is important to recognise that PPIE in animal research is not something that all lay members feel comfortable with. Some charities have developed processes for opting in and/or opting out of certain types of research.

 *“We run an opt-out for our [involved lay members], that if they don’t want to review biomedical research, then they don’t have to.”*

Stephen (Research Involvement Professional, Large Medical Research Charity)


This is a way of enabling people to participate in research on their own terms, reducing the potential for exclusion, discomfort, and bias shaping reviewing and scoring. Some lay members recognised this as a useful strategy, though others are so enthusiastic about being involved that they do not want to limit their opportunities.

5.2 Connecting PPIE to cultures of care

PPIE is usually justified in terms of patient empowerment and the contribution that patient and public perspectives can make to research trajectories. These are important aspects and are the focus of most efforts to evaluate PPIE. However, from our analysis we propose it is also valuable to consider how PPIE with animal research can enhance the cultures of care across health and research.

A '*culture of care*' is a term used to describe an institutional context that is designed to encourage service providers to care about those they care for, those they work with, and the work they do. A culture of care is now central to ideas of NHS service delivery, with a focus on providing good care for patients, supporting caring staff, and empowering both to speak out if they find things that are wrong. In the context of animal research, institutions are required to create a culture of care for the animals they use through demonstrating respectful and humane attitudes towards animals used in research, in ways that meet societal expectations.⁸ In both contexts, the idea of a culture of care recognises the importance of empowering individuals and making links between institutional responsibilities and wider social expectations. The growth of PPIE with animal research has the potential to add to conversations around cultures of care within and outside of the laboratory.

Firstly, care and concern for animals is explicitly expressed by publics and lay members. Many want to be actively involved in influencing and shaping practices of care and animal welfare. If a culture of care is informed by societal expectations, lay members increasingly see their role as contributing to this interface as people with a concern for both animal welfare and an interest in the best way to realise benefits from research and reduce waste.

 *"I think it is almost being, not being guardians but we can look out for the animals' interests, that's really where I would see my involvement. And also challenging that using them was the best and most effective way of running that particular trial. Does it actually have to use animals?"*

Tabitha (active in research involvement for over 5 years)

⁸ Animals in Science Regulation Unit. 2015, page 4. Identification and Management of Patterns of Low-level Concerns at Licensed Establishments. London, UK: Home Office. Accessed January 29, 2019.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/512098/Patterns_low-level_concerns.pdf

- 🍷 *“My questions will be how many mice and for how long and have they struck the right balance between something that’s statistically valid but to keep the numbers as low as possible? Are there alternatives that were considered?”*

Rachel (active in research involvement for over 5 years)

PPIE processes create opportunities for lay members to question whether alternatives have been considered, how the 3Rs have been implemented, and whether research will be adequate to produce meaningful translational benefit for the harms invoked. There are opportunities to consider how to further equip lay members with the confidence and expertise to approach and raise these questions, though in ways that are sensitive to the lived experiences and illness narratives of lay members.

Secondly, publics and lay members not only shape a culture of care, they are also seen as a key audience for the animal research sector to convey a culture of care to. Lay members are increasingly empowered stakeholders, having a say on what research is funded, as well as asking questions about how research is conducted. Lab tours and other involvement and engagement events provide opportunities to convey a culture of care to this group, by being open about research and regulation.

- 🍷 *“It’s this thing that if you’re not open and transparent, people will fill the void and knowledge with something negative. So if you just show them that actually, we stand by and feel that we’ve got a great level of animal care and husbandry and we’re happy to show you about all the things we do, it’s absolutely huge.”*

Tom (Research Involvement Professional, Medium Medical Research Charity)

- 🍷 *“That’s one of the benefits of [involvement], our volunteers do see the 3Rs in action and the care and affection that some of our researchers have for the animals that they use in their research, and how the Home Office regulations are applied in practice.”*

Stephen (Research Involvement Professional, Large Medical Research Charity)

Thirdly, publics and lay members are an additional group the animal research sector has to consider when practicing and producing a culture of care. PPIE raises practical concerns that have to be carefully considered to create positive experiences.


- 🍷 *When you’re dealing with people with [condition] you have to think about access and everything else very carefully, but also just the logistics about people with [condition] generally can’t sit for an hour in a lecture or anything like that, it’s got to be bite sized chunks, small things. We offered lab tours but then of course you have to offer the opportunity of not doing a lab tour if you’re not physically mobile, all those kinds of things.*

Robert (Biomedical Researcher, University Sector)


Research organisations have to consider how activities will work in contributing to cultures of care for patients and animals. This includes asking questions around who patients will meet, what animals patients will meet, and how will their physical needs and the emotional aspects of engagement be accommodated. It also includes questions around how PPIE can contribute to the culture of care within a research facility, including supporting animal technicians, ensuring animals are not impacted, and considering how to respond to the expectations of lay members towards the use of animals in

research. These are important considerations, but also open the opportunity for PPIE activities to contribute to creating and sustaining cultures of care across health care and research contexts.

However, even if PPIE provides an opportunity to strengthen cultures of care, it is important to realise that working with patients has not previously been part of many researchers work. Researchers recognise that doing high quality and meaningful PPIE requires time and resource. Whilst they may have an interest in working with lay members, they do not always have the capacity to do so.


 *“I think there are increasing pressures on us as academics, to do more and more with less and less.”*

Roy (Biomedical Researcher, University Sector)

 *“There’s a huge time investment from the scientist and it’s one of those things where you have to be skilled in lots of different areas. To do this takes a lot of time and energy, and I enjoy doing it, but engagement and involvement take up a lot of time.”*

Sian (Biomedical Researcher, University Sector)

It is also important to recognise that researchers working in pre-clinical contexts may not have regular experience of meeting, talking to, and working with people affected by the health conditions they study. When it comes to involvement and engagement, they may not feel trained, equipped, or comfortable in having those interactions.

 *“There’s an emotional cost to the scientist. The number of scientists I’ve met who have never seen someone with the disease that they’re working on. [...] And again, there’s no back-up or support whereas at least if you’re in a clinical environment perhaps you’re more resilient or more prepared for that.”*

Sian (Biomedical Researcher, University Sector)


Understanding that PPIE in animal research involves elements of care for lay members, animals, animal technicians, and researchers is important. Involving lay members in PPIE with animal research involves multi-dimensional relationships between people with diverse perspectives. PPIE presents opportunities to shape cultures of care around health and animal research, but they also need to be carried out with care that is attuned and sensitive to the differing needs and experiences of all involved.


5.3 Training for involvement and engagement

Many of the activities around PPIE with animal research are still experimental, with limited guidance available to guide different groups through activities, and incomplete evaluation to inform practitioners on the best approach for different contexts and questions.


Lay members recognised that being involved in animal research brought specific questions, languages, and challenges, that they did not always feel equipped to deal with. Though most reported being happy to ‘have a go’, or searching the internet to develop a better understanding, there were

concerns that they were not fulfilling their potential as involved lay members. Many felt that more support was required to enable them to engage more meaningfully with research that involved the use of animals and ask important questions. Asking lay members for their input into research without fully equipping them risks instrumentalising processes of involvement and disempowering people. Lay members need to be well informed and given honest and realistic information in order to make meaningful contributions.


 *“I did wonder what a mouse model was! I got one that didn’t explain it!”*
Rhoda (active in research involvement for over 3 years)

 *“At least from my perspective, when I think about animal research, I am thinking about LD50, ED50 type of stuff where we are just testing toxicity essentially. I hadn’t quite realised just how creatively the animals are sometimes used. It would be interesting at least to explore or to educate patient representatives on how animal models aren’t just mice being prescribed a drug.”*
Tristan (active in research involvement for over 3 years)

However, even when lay members feel able to ask questions they may not know what to do with the answers. As a result, lay members frequently identified that they wanted more training on the specifics of animal research. This training may be as much about empowering as equipping lay members with scientific expertise. This training also needs to recognise and account for lay members’ expertise. Conversations strongly framed around one or other groups’ ‘deficits’ of knowledge tend to reinforce barriers to communication, pushing people to defend existing positions and strengthen links between identities and attitudes, and can lead to inaction.

 *“I think we could do more on the training. Particularly around maybe language, common terms that scientists will use [...] in a way that was usable for people, for lay people. More of that would be brilliant. [...] Within the [involvement community], there must be a group of us who are monitoring animal research and maybe therefore there is a case.”*
Rachel (active in research involvement for over 5 years)


Lay summaries should be written in plain English, avoid the use of sector-specific jargon or acronyms, and explain any technical terms used. There is also a need to consider how lay members read and interpret the information that is provided. Putting issues around animal research into a dialogue with lay people requires cultivating a sensitivity to how lay members might read technical summaries as representing researcher views of animals in research. The (often-stark) language used by scientists to describe practices within animal research can actively affect communication and understanding; being aware of language and phrasing is key in order to open up genuine dialogue, convey cultures of care, and prevent potential misunderstandings and alienation.

 *“There was one application I got in particular and the way they talked about the mice, I can’t remember the analogy they used but it was very much they’re just throwaway things. I was fuming, and I sent a stinking comment back, saying ‘I really hope you don’t fund this, and I*

hope you give this feedback back to the researcher'. I was quite shocked that a researcher in this day and age would put that in an application."


Tabitha (active in research involvement for over 5 years)

Many pre-clinical and translational researchers reported they were involving lay members in their research as something of an experiment in itself. They also identified training as a critical for encouraging the growth of PPIE in this area of science:

 *"[We] really pushed for that training programme to include PPI training for researchers, and it does now and that's proved extremely popular. There's an element of academic institutions providing training for their early career researchers in this area. [...] At an institutional level, if those things are in place, that encourages researchers and scientists to think, 'well hold on a minute here, maybe this is something that I could be doing outside of that open day and actually it would add something to my research'."*

Scarlett (Biomedical Researcher, University Sector)

Many researchers recognised that charities offer excellent training on PPIE in general. However, they felt training needed to be tailored to the particular challenges of identifying opportunities for PPIE in pre-clinical research and to opening up questions around animal research to which lay members could contribute. This challenge was also identified by research involvement professionals.

 *"When we do our training, researchers, sometimes after the training say, 'That's all well and good but I can't really work out how it would fit in the context of my work?'. What really does help is when you have an example of someone that they go, 'Oh I do very similar research' or 'I see myself in this person and their research, they're doing something'. To build that case study and to build that evidence base is really helpful and anything that we could use in order to kind of influence those basic researchers, those doing animal studies, would be really useful."*

Tim (Research Involvement Professional, Large Medical Research Charity)


Lay members, research professional and researchers all suggest the lack of training in this area is a potentially limiting factor in the further development of PPIE around animal research. However, they also suggest that training will depend on identifying more case studies and providing a stronger evidence base around what works. At the moment, we do not have these case studies. We intend to work further with the community to identify and develop these.

However, the conversations across lay members, engagement professionals and researchers do identify common questions around how PPIE around animal research might further translational research, support cultures of care and widen processes of harm-benefit analysis. This offers scope to broaden definitions of what is working and worthwhile in the evaluation of PPIE with animal research in order to identify and evaluate further relevant case studies.


5.4 Connecting up and feeding back from PPIE

Whilst patches of innovation were identified in the interviews, many respondents suggest that furthering meaningful PPIE with animal research requires connecting up different instances and processes. Lay members are specifically concerned about receiving feedback that validated their contribution and offered them the opportunity to learn more if needed. Researchers are particularly interested in how to align the pressures that they were under and access the time and resources required to do PPIE effectively. Medical charities and funders, many of whom are driving developments in PPIE, are seen as vital nodes in the networks required to connect these elements.

Obtaining feedback from their work is particularly important to lay members, given that the subject of animal research provokes technical questions and ethical issues that individuals struggle with. Their questions often arise from ethical and emotional concerns, rather than practical and technical questions that systems of PPIE are more used to dealing with. Some questions about research applications could be easily addressed with feedback following review.


 *“If you think they’re using too many or whatever then you can ask the question. We don’t get the feedback on the answer.”*

Tabitha (active in research involvement for over 5 years)

 *“I get very frustrated because we get no feedback, I always have quite a lot to say [...] but you never hear anything, you never hear any feedback, I really don’t like that. I would like to have feedback.”*

Tracy (active in research involvement for over a year)

Other questions emerging from lay member review are more extensive, and again show how involvement blurs with engagement; in this case research involvement in biomedical review leads to an interest in furthering engagement around animal research.

 *“If there was that facility to learn a lot more about how many animals would be used, where the animals were coming from, how they’d been treated, maybe if there was that facility to ask a lot more then maybe I’d take it up, but it hasn’t really seemed possible, in terms of what I’ve been involved in so far.”*

Tina (active in research involvement for over 3 years)

Groups like the Shared Learning Group on Involvement in Research⁹ are well placed to provide guidance on these issues. Indeed, several of the lay members interviewed mentioned reading the Shared Learning Group’s ‘involving people in laboratory based research’ discussion paper for advice and guidance on how to fulfil their roles when they faced challenges in understanding their role in basic research projects.

⁹ See <http://slginvolvement.org.uk/> (NB this group is considering a name change in 2019)

There was also a sense that funders needed to both provide clearer guidance, and a clearer steer on expectations of involving lay members in animal research:

🍷 *“I’ve heard all sorts of excuses. Sometimes it’s cultural issues about, ‘we can’t talk to patients because of this, that and the other’. And I just don’t buy that as a reason not to do something, I think there are ways around it. And I think as a sector, as funders, we are in the position to hold people’s feet to the fire and say, ‘Come on, you’ve really got to do better’. Or ‘We can help you, work with us and we can try and use our networks to act as a facilitator as well’. It’s down to other funders to make that possible, it’s down to us to listen to patients, to find out as well what they want and how they want to be consulted.”*

Sean (Research Involvement Professional, Small Research Support Charity)

🍷 *“I think that’s one of the issues with the upstream, you can try and generate as much goodwill as you want but until the money folks say, ‘Okay’. Actually my involvement with PPI was because [funder] said, ‘No matter what your grant, if you’re working on worms in a dish or mice, we really want you to do some PPI and you’re going to tell us how you’ve done that on the grant application’.”*

Robert (Biomedical Researcher, University Sector)

Funders hold a lot of power in deciding the direction and level to which lay member involvement in animal research develops. This decision can be informed by the potential value the conversations within PPIE with animal research may have for furthering translational research, contributing to cultures of care, and widening harm-benefit analysis. Implementing meaningful PPIE with animal research requires commitments to providing time, resources and training; sharing learning across the cross-sector sharing; and offering feedback to lay members.

6. Further work

At this stage in our research we would like to draw on the interviews, our participation in events, and the lay member workshop to identify some preliminary recommendations for discussion with those who have been involved in our research. We also explain the next steps for our work. We invite your comments and contributions.

6.1 Preliminary recommendations

Drawing on the common themes and challenges identified in the interviews, we suggest there are further opportunities to develop PPIE with animal research that is accessible and meaningful for all involved. Our preliminary recommendations include:

- 🌀 **Funders need to be clear about the extent to which PPIE with animal research is a priority** for research. If it is to be significant, then creating appropriate time, space, and resource for relationships to develop and for these activities to be conducted and evaluated in a meaningful manner is important.
- 🌀 Working across the sector and providing more **opportunities to connect involvement and engagement activities** would have benefits. Good involvement is informed by good engagement, and what is valued most by lay members is authentic conversations and two-way dialogue in appropriate language. Engagement can enable lay members to feel more empowered and comfortable in being involved in research that uses animals, as well as inspiring more people to seek out opportunities to be involved. Researchers can learn from conversations in both involvement and engagement events.
- 🌀 Organisations and funders facilitating PPIE with animal research need to be aware of the unique technical challenges that come with extending PPIE into basic and preclinical research and the ethical and emotional issues associated PPIE with animal research. This requires **additional measures for evaluating and developing the evidence base around PPIE** with animal research, beyond the delivery of better research. These should reflect lay member concerns but could draw on frameworks such as those around **harm-benefit analysis** and **cultures of care**.
- 🌀 Across the sector, there is a need to recognise that an **involvement or engagement with animal research is not for everyone**. Organisations and funders that facilitate PPIE should create processes that enable people to encounter animal research on their own terms and to the extent with which they are comfortable. This could be about providing mechanisms to opt in or out of certain types of research, providing content warnings, or a staged process for learning more.

- 🍷 Organisations and funders that facilitate PPIE should offer **additional training for lay members** who want to learn more about animal research to enable them to engage with more confidence with the topics and material they are asked to be involved in. Such training could be about equipping lay members with an understanding of what may be useful questions to ask of the different stages of animal research (and how to interpret answers to such questions), or frameworks for connecting the technical and ethical questions that they have (e.g. 3Rs, Harm-Benefit Analysis).
- 🍷 **More resources are needed for lay members** who do come to be involved in animal research. Animal research comes with a specific terminology that not only refers to the technical aspects of research, but language choice and phraseology also conveys to lay members something about how they think researchers view animals. Researchers need to consider this, and engagement professionals could develop informative glossaries and plain language summaries of common concepts and practices, to enable more open and informed lay involvement. Lay members need to be well informed and given honest and realistic information in order to make meaningful contributions.
- 🍷 **Organisations and funders that facilitate PPIE need to provide feedback to lay members** about their questions and concerns relating to animal research. Feedback is important in alleviating anxieties and building capacities, skills, and interests in being involved in research projects using animals.
- 🍷 Organisations and funders that facilitate PPIE should offer **training on involvement and engagement for research staff** that is customised to the topic of animal research and the additional preconceptions, challenges, and sensitivities that need to be navigated, through tailored case studies of innovative good practice and evidence based examples of where PPIE has made meaningful improvements to research. As well as ensuring these events are open to researchers across career levels, there is the opportunity to invite animal technicians and other facility staff to be part of these conversations.

6.2 Next steps

Our research is still ongoing, and these are preliminary findings and recommendations. This report was written 18 months into our 5 year Wellcome Trust Collaborative Award (2017-2022). We are continuing our research with the community, with additional interviews and workshops, more detailed analysis, further dissemination targeted to different stakeholder groups and academic journals, and integration into the wider work of the Animal Research Nexus project (see [Annex](#))

In the next phases of our research, starting in 2019, we will build on our initial explorations, recognising the challenges and opportunities identified, to consider how people can have more comfortable, meaningful, and productive conversations about animal research within the context of PPIE. We list our future plans below and look forward to your contributions to our work.

We plan to convene a stakeholder and scientist workshop to discuss current challenges and future opportunities for PPIE with animal research

Based on the success of our previous workshop, which brought together lay members from across the biomedical research sector, we would like to run a similar event bringing together research involvement professionals and scientists, along with lay members active in research involvement, to discuss issues around PPIE with animal research. This would enable different stakeholders to explore further the opportunities and challenges we have identified and help develop evaluation criteria, case studies and training guidelines.

- 🌐 *In identifying priorities for moving forward, participants at the workshop suggested that we should run a similar event with scientists and research funders. Participants wanted to know ‘how their involvement has helped’ and understand what does ‘lay’ mean for the people whose committees lay members sit on.*

Extract from ‘Lay Members in Biomedical Research’¹⁰

We will seek to identify and collate a series of case studies highlighting opportunities for PPIE in animal research.

A range of different stakeholders have requested case studies of good practices and innovation regarding PPIE around animal research. Short case studies would help to demonstrate some of the impacts and benefits of PPIE with animal research and start to develop an evidence base around how these interactions can be valuable and helpful. Case studies of good practice would emphasise the imaginative ways that different organisations and researchers have embraced PPIE with animal research. Rather than advocating a wholehearted (or tokenistic) introduction of PPIE with animal research, these case studies will likely demonstrate situations where involvement and engagement can be productive and meaningful and explore the active links between involvement and engagement.

This would also involve collecting case studies of strategies for identifying and managing situations where lay members do not want to engage with animal research. We will do this through further analysis of our existing research data, further qualitative interviews, and using the stakeholder workshop to identify examples of good practice.

- 🌐 *“I think it’s very much in our space to be able to show case studies, explain what other people are doing, talk about different ways of doing things. That could involve all sorts of different things from new funding initiatives, to collaborations, to the patient voice. [...] We have an opportunity to share that working and say, ‘Here’s how, for instance, [organisation]*


¹⁰ <https://animalresearchnexus.org/publications/lay-members-biomedical-research-report>

are involving patients in their research and here are all the different things that they can do'. It's sharing the ideas and the case studies with others and saying, 'go and talk to them' or 'we can put you in touch' or 'learn more about what they're doing, if you would like to do something yourself'. Rather than everyone sitting in their own organisations, almost fishing in the dark, trying to figure out what they should do and how they can perhaps involve people."

Sean (Research Involvement Professional, Small Research Support Charity)

We plan to produce short guidance around the training needs that exist for lay members and researchers interested in PPIE and animal research

A lack of training on the specific opportunities and challenges that animal research brings to involvement and engagement practices was frequently recognised as a barrier. Building on the development of case studies, we will construct short guidance from our more detailed analysis on how to manage expectations, anxieties, and common concerns and questions of different groups. Drawing on our existing research data, further qualitative interviews, and the expertise of key stakeholders within the sector, we will provide recommendations and resources around potential training requirements. This would identify training needs that could be taken forward by medical research charities and funders. It would encompass the training needs for researchers interested in involving and engaging people in their work and also for lay members who come to take on an active role within animal studies.

 *"I see PPI coming up more and more and I think that yes, there needs to be training but from the first principles; what it is, what it's good for. It would be really nice if we could have in that kind of training, some definitive examples of where PPI was a benefit to the researchers."*

Robert (Biomedical Researcher, University Sector)

We will produce a series of academic outputs on the topic of PPIE and animal research connecting our work to ongoing debates around public involvement, harm-benefit analysis, translational research practices, and cultures of care in biomedical research

In addition to making a contribution to stakeholder debates around PPIE with animal research, our research also has contributions to make to the growing body of academic literature on involvement and engagement, ethics, and translational research in the social sciences. We believe this work has valuable contributions to make to academic debates that seek to conceptualise and understand the role that involvement and engagement can play in health research and the literatures exploring the operation of ethics and development of culture of care in animal research. Specifically, we plan academic outputs that:

- 🍎 Develop understandings of how taking PPIE into preclinical and laboratory research may change knowledge production and translational research practices.
- 🍎 Explore PPIE with animal research from the perspective of the lay members in more detail to understand the relationship between the technical, ethical, and emotional elements of their experiences.
- 🍎 Expand what we know about how people implement Harm-Benefit Analysis to include patients and publics.
- 🍎 Consider how PPIE might be involved in building and conveying a 'Culture of Care' across the sector.
- 🍎 Connect to our work on PPIE to the wider Animal Research Nexus programme, for example in connecting to how laboratory vets construct their responsibilities to human patients.

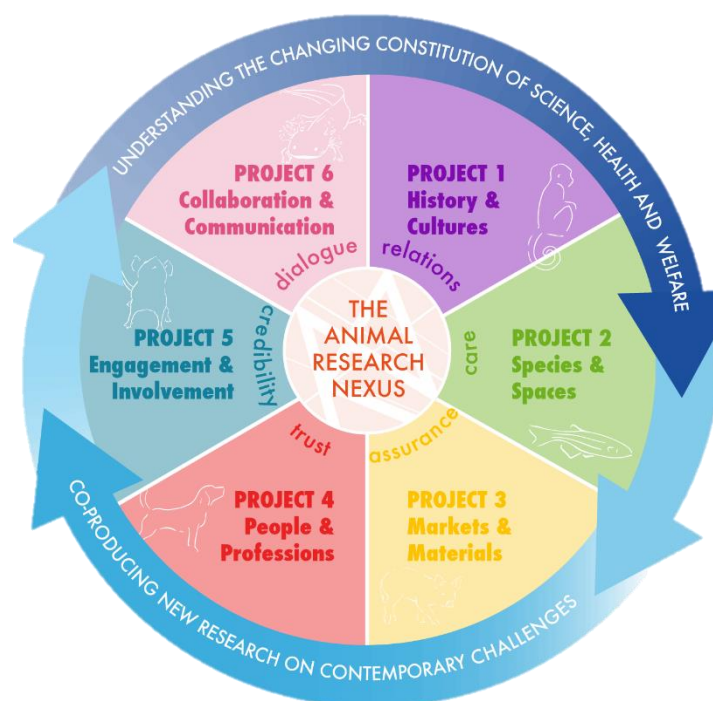
We recognise this report has only begun to open up questions around PPIE with animal research, and that understanding how people might challenge, shape, and change research agendas will require more discussion.

Annex: The Animal Research Nexus Programme

Animal research is contingent on a complex network of social relations and ethical obligations across science and society, which are both formally constituted through law, and informal or assumed. These entanglements can be understood as the Animal Research Nexus.

Our programme of research seeks to understand the historic and present-day links between science, health, and animal welfare, to identify the emerging challenges to laboratory animal research, and to build new conversations around them. Our programme has several strands exploring these challenges from different perspectives. We are interested in the histories and current practices that are shaping the kinds of species, places, professional roles, and patient expectations associated with animal research.

We are a group of 15 researchers from five institutions (University of Exeter, University of Manchester, University of Nottingham, University of Oxford, and University of Southampton). We have a range of disciplinary backgrounds that include the social sciences, humanities, and veterinary sciences. Many of us have previous experience of working on laboratory animal research. We also all have experience of working with different public and stakeholder groups, including scientists, patients, publics, and policy-makers. We are working in partnership with a number of scientific research establishments and are overseen by a Programme Advisory Committee that represents the range of interests across laboratory animal research.



This research aims to inform academic debates, contribute to the development of policy, and inspire public debate. Research outputs will include academic publications, including books and international journal articles in social sciences and humanities; research reports in policy-relevant journals; short briefings for policy, practitioners, and public audiences; and stakeholder dissemination and public engagement activities. For more information, see <https://animalresearchnexus.org/>