



INFORMING INVOLVEMENT AROUND ANIMAL RESEARCH

REPORT AND RESOURCES FROM THE
ANIMAL RESEARCH NEXUS PROJECT

Gail Davies, Richard Gorman, and Gabrielle King



ACKNOWLEDGEMENTS

This report is the product of many conversations and interactions with people affected by health conditions, involvement and engagement professionals, scientists and other academics. We learnt so much from each person who took part and who encountered our work. We are extremely grateful to you all for your generosity, expertise, and time.

We would like to offer our particular thanks to Bec Hanley, Penny Hawkins, and Kristina Staley whose critical reading, suggestions, and guidance have been crucial to us in making sense of what we wanted to say, in identifying new aspects, and in pointing us in the direction of resources and areas of interest. All remaining omissions and errors are of course our own.

We would also like to acknowledge the generous support of the Wellcome Trust who funded this work through their collaborative award to The Animal Research Nexus Programme (Grant no: 205393/Z/16/Z).

All the resources linked to in this document were last accessed in March 2022. Please do let us know if you encounter any broken links and we will be pleased to update these.



SUMMARY

This report contributes to a growing body of advice around how to involve people affected by health conditions in laboratory or biomedical research. Involvement is now increasingly well established in clinical and health services research. Extending involvement to laboratory research can help to ensure that this work is also as relevant as possible to people affected by different health conditions. However, there are challenges to involvement in laboratory research: terminology can be different and complex, research takes place in unfamiliar locations, and conversations can involve sensitive topics like animal research.

Where does this report come from?

This report focuses on practices of involvement that include discussions of animal research. It draws on work completed as part of the Animal Research Nexus Programme (2017-2023). Our research at the University of Exeter looked at the opportunities and challenges around involving people affected by health conditions in conversations about animal research in the UK. We researched individual perspectives from i) people affected by health conditions, ii) research scientists, and iii) engagement and involvement professionals, and used workshops to bring these conversations together.

Our earlier analysis sought to understand the differences between these perspectives and is written up in academic articles and an interim report. You can access these at

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

What does this report do?

This report brings together our findings and identifies resources to help people think across these different perspectives. It is organised around the moments when people affected by health conditions may be involved in conversations around animal research, including:

- **Opening up conversations** about animal research
- Preparing for **site visits**
- Exploring **how to talk about animal models** from different perspectives
- Understanding how **involvement and ethical review processes** are related
- Outlining how **institutions and research cultures** can **better support involvement**

Each chapter outlines the different views you may find if you are involved in conversations around the use of animals in laboratory research. It also identifies key factors to consider when starting involvement. We include annotated lists of further reading and references, which we think can help support people taking part in involvement around animal research.

If you have any further questions or comments about our research, you can get in touch with Gail Davies on G.F.Davies@exeter.ac.uk.

CONTENTS

Acknowledgements	b
Summary	1
Terms used in this report	4
1. Introducing involvement around animal research	8
1.1 Involvement in laboratory research	8
1.2 Involvement around laboratory animal research	8
1.3 Reading this report	10
1.4 References and further resources on involvement in laboratory based research	12
2. Background research	14
2.1 The Animal Research Nexus Programme	14
2.2 Understanding different perspectives	15
2.3 Generating new conversations	15
2.4 References and further resources on involvement and engagement in the Animal Research Nexus Project	17
3. Opening up conversations about animal research	19
3.1 Key Points	19
3.2 Openness, engagement, and involvement	19
3.3 For people affected by health conditions	20
3.4 For researchers and scientists	21
3.5 For involvement and engagement practitioners	23
3.6 References and further resources on starting conversations around animal research	24
4. Placing dialogues about animal research	26
4.1 Key Points	26
4.2 Preparing to visit an animal facility	26
4.3 For people affected by health conditions	27
4.4 For researchers and scientists	28
4.5 For engagement and involvement practitioners	30
4.6 Virtual involvement	30
4.7 References and further resources on the placing and places of patient involvement	31

5. Talking about animal models	33
5.1 Key Points	33
5.2 What is an animal model?	33
5.3 For people affected by health conditions	34
5.4 For researchers and scientists	36
5.5 For involvement and engagement practitioners	37
5.6 References and further resources on translational research and animal models	39
6. Considering ethical review	41
6.1 Key Points	41
6.2 Who reviews animal research funding proposals?	41
6.3 For people affected by health conditions	43
6.4 For researchers and scientists	45
6.5 For engagement and involvement practitioners	46
6.6 References and further resources on ethical review	47
7. Continuing conversations around involvement	49
7.1 Key points	49
7.2 Culturing care in research involvement	49
7.3 Enhancing involvement within institutions	50
7.4 References and further resources on involvement and research cultures	51
8. Conclusions	53



TERMS USED IN THIS REPORT

We use a variety of terms in this report. You may use these words differently in your practice and it may be helpful to talk with the people you are working with about the terms you all prefer. Different countries use different terms for these processes. We're writing from our perspective in the UK.

Animal research and testing is carried out for a range of purposes including to understand biological processes, to learn more about disease, and to develop and test new drugs and treatments for humans and animals. The care and use of animals in research and testing is covered by different aspects of UK law. It is regulated by the Animals (Scientific Procedures) Act 1986 (ASPA, see below). There are also regulations that, directly or indirectly, require animal use. By law, new medicines currently need to be tested on animals before they can be licenced for use in humans. If scientists do use animals, they have to follow regulations under ASPA designed to minimise the pain, distress, and harm caused to these animals.

Animal Welfare and Ethical Review Body (AWERB) is a committee required under ASPA in the UK, in establishments where animal research takes place (like a university), as well as establishments that breed, or supply, animals for laboratory research. One of the AWERB's tasks is to review each project licence application and advise the establishment licence holder whether to support these from an institutional perspective. AWERBs have to include people at the establishment who have responsibilities for animal research and welfare, like scientists, laboratory animal veterinarians, and senior animal technologists. (Animal technology is a specialist profession responsible for the care and welfare of laboratory animals.) AWERBs are also encouraged to seek a wider membership than the minimum required, and to include lay, or independent, members.

The Animals (Scientific Procedures) Act (ASPA) was passed in 1986 and updated in 2012. It regulates the use of animals in research and testing in the UK. ASPA protects all vertebrate animals, such as mammals, fish, and birds used in procedures for scientific and medical research. A revision to the act extended this protection to include cephalopods, like octopus. ASPA defines a regulated procedure as one that causes an animal pain, suffering, distress, or lasting harm that is equivalent to, or greater than, that caused by the expert insertion of a hypodermic needle.

Engagement in research refers to the sharing of knowledge and information. Engagement can be targeted at specific groups, such as patient groups, or the wider public through open days and science festivals.

Harm Benefit Analysis is a requirement under ASPA. It is a process for assessing whether the harms that are expected to be caused to animals are justified by the benefit the research is likely to have. Harms can be rated as 'severe', 'moderate', 'mild' or 'non-recovery', in which an animal is used under general anaesthetic and not permitted to recover, i.e. they are humanely killed while still unconscious. The harm-benefit analysis process is undertaken by the Home Office's Animals in Science Regulation Unit (made up of veterinary or medically qualified inspectors). The outcome of the harm-benefit analysis determines whether an application to do research using animals is approved or refused.

Involvement in research refers to research that is carried out in active partnership. It involves doing research 'with' people (in this case, those affected by health conditions), rather than 'to' or 'for' them. There are lots of debates about the most appropriate terms to use to talk about involvement and engagement. We use the NIHR's (2021) definition of involvement as it helps clarify the difference between engagement and involvement. Public engagement is increasingly found around animal research, but involvement is still much less common.

Laboratory research is sometimes also called 'preclinical' or 'basic' research, or 'discovery science'. It takes place to understand more about biological processes. The research might also be used to test the safety, feasibility, and efficacy of a potential treatment or therapy. Laboratory research enables testing to take place in a controlled environment. Animal research is part of laboratory research.

Licences are required for all regulated procedures on protected animals carried out under ASPA. These licences are approved by the Animals in Science Regulation Unit, or ASRU, which is located in the UK Home Office. All research conducted on animals must have the following licences approved before any work can commence.

- An **Establishment Licence** is required for the premises where animal research will take place and sets out the responsibilities of that establishment, including the role of the Establishment Licence Holder.
- A **Personal Licence** is granted to the researchers conducting research, after they have undertaken training to demonstrate they have the competency, experience, and necessary skills for carrying out regulated research and procedures.
- A **Project Licence** details the project-specific research that will be carried out, explaining the benefits of the work, and indicating how the harms to animals will be minimised. A project licence will only be granted if there is judged to be a positive overall harm-benefit analysis. Licences are granted for a maximum of five years to a named individual who has a personal licence and is working at a licenced establishment.

Openness Agenda refers to a set of initiatives to support organisations, animal technologists, and scientists in the UK who use animals in research to talk openly about their work. At the heart of this effort is The Concordat on Openness (<https://concordatopenness.org.uk>) which is a set of commitments for UK-based life science organisations to enhance their animal research communications. The Concordat was launched by Understanding Animal Research on 14 May 2014 and had 127 signatories in 2022. Signatories to the Concordat have agreed to be more open about their use of animals in research, including: 1) being clear when, how and why they use animals in research; 2) enhancing their communications with the media and the public about their research using animals; 3) being proactive in providing opportunities for the public to find out about research using animals; and 4) reporting on progress annually and sharing their experiences.

People affected by health conditions describes those diagnosed with health conditions, and those who are affected by conditions as family members, carers, and sometimes friends. Other organisations might use different terms, like referring to people as 'patients', 'volunteers', or as members of research networks, panels, or lay faculty. The term 'affected by' enables us to identify the expertise and experience people have beyond their health condition.

Translational research is research that helps develop the practical application of findings from laboratory science into new treatments in the clinic. It is often referred to as moving from 'bench' to 'bedside'. In practice, translation is not a linear process and there often remains a gap between laboratory research and clinical application. Translational research often involves moving between different research methods, including using computer models, tissue culture, animal models, and data from clinical studies.

The 3R's refer to three principles: the replacement, reduction, and refinement of the use of animals in research. These principles are now embedded in UK legislation as a way to reduce the harms experienced by animals used in research and testing. The 3R's refer to three specific processes:

- **Replacement** refers to methods that replace the use of animals in research. This might be through computer modelling, techniques like tissue cultures (including Non-Animal Technologies such as 'organs-on-chips'), or the safe and ethical use of human volunteers to address scientific questions
- **Reduction** refers to methods that minimise the number of animals used in experiments, whilst still ensuring that results are statistically valid
- **Refinement** refers to reducing suffering and improving welfare throughout an animal's lifetime. This includes using methods that minimise suffering during procedures carried out on animals, and refining housing, husbandry and care, for example by ensuring mice have sufficient, good quality nesting materials

1

INTRODUCING INVOLVEMENT AROUND ANIMAL RESEARCH

1. INTRODUCING INVOLVEMENT AROUND ANIMAL RESEARCH

1.1 Involvement in laboratory research

People diagnosed with health conditions and their family members and carers are increasingly being asked to contribute their perspectives to help improve the quality and relevance of research. This can include their contributions to setting research priorities, shaping clinical trials, and informing how clinical care is delivered. People affected by health conditions are recognised as having important knowledge and experience to contribute. They are also often the intended beneficiaries of new research, and many argue this means they have a right to be involved in the practices that inform their treatment and care.

Over the last three decades, initiatives to include people affected by health conditions in research have gradually moved from health and care research into laboratory research. Laboratory research refers to preclinical biomedical research that is further 'upstream' in the development of new understandings of disease or new potential treatments.

Involving people in laboratory research brings some challenges. There is less experience of upstream involvement to learn from, there are different technical languages to negotiate, and there are more uncertainties around the potential benefits of research because it is further away from clinical outcomes. A 2019 report on *Patient and Public involvement in laboratory based research*, led by Bec Hanley, outlines how involvement can add value to laboratory research. However, there are additional factors to consider around language, communication, and being sensitive to the health needs of those who are involved. Bringing animal research into these conversations adds further sensitivities and complexities.

1.2 Involvement around laboratory animal research

This report focuses on research that includes the use of animals. Animals are still used in some laboratory research that is focused on understanding disease and drug development, and in testing the safety and efficacy of potential drugs and treatments. People affected by health conditions have valuable contributions to make to these discussions, including identifying and prioritising the research that is most important to them.

Our research indicates that many people value having answers to their questions about the use of animals in research. However, there are many issues to consider when talking about animal research. Conversations around animal research have to navigate different perspectives, ethical sensitivities, and complex histories. Many scientists find talking about animal research difficult given past security issues and the continuing sensitivity of this topic for many people. The boundaries between scientific and ethical discussions are also blurred in this area: many debates around animal research are set up through polarised pro- and anti- animal research positions, which can limit opportunities for meaningful dialogue and lead to uncertainty around anticipated outcomes of involvement.

Despite these challenges, many people affected by health conditions are already involved in a range of conversations about animal research. In our research, we have talked to people involved in the following activities:

- Attending events and **visiting laboratories** to learn more about a health condition from researchers
- Setting **research priorities**, agendas, and strategies with medical charities
- Working with researchers to help develop **research proposals**
- Sitting on **funding panels** that help organisations decide what research to fund
- Reviewing, ranking, and **scoring research proposals** and making decisions about whether the research addresses important and relevant questions
- Being involved in **steering groups** and visiting researchers in their laboratories to help monitor the progress of projects
- **Disseminating research findings** and talking about research to charities, peers, and others
- Sitting on **ethical review panels**, like Animal Welfare and Ethical Review Bodies (AWERBs), in what is referred to as a 'lay member' capacity

It is important to understand that not everyone affected by health conditions will feel comfortable talking about animal research. They may want to focus upon other kinds of laboratory research, or to share views on why they might not want to be part of these conversations. These can also be valuable perspectives. If you are a scientist or an engagement and involvement professional, you might want to consider why people step away, who does not want to be involved, and what is missed by not including them in the conversation. They may be asking critical questions that are a productive challenge to the way that research and involvement are currently organised. However, we do not deal with this aspect in detail as it was not part of our present research.

1.3 Reading this report

This report contains questions and good practice suggestions for helping people affected by health conditions, scientists, and involvement and engagement professionals who are having conversations about animal research. We have included short summaries from our research and highlighted the different resources available to think through these challenges. We do not suggest there is one 'best' way for involving people in discussions about animal research: rather we have identified things that may be helpful to consider in different forms of engagement and involvement.

Who is the report for?

We have written this report primarily for people affected by health conditions, research scientists, and involvement and engagement practitioners. These categories are complex and dynamic, and so we set out how we use them in this context:

- **People affected by health conditions** includes people diagnosed with a health condition, family members, friends, and carers
- **Scientific researchers** refer to people who are working on laboratory or preclinical research
- **Engagement and involvement practitioners** are those responsible for facilitating events with people affected by health conditions and wider publics. Engagement and involvement practitioners might work within organisations, like charities, or within research institutions and groups

We use these groupings in the report as a way of splitting up chapters and making sure our suggestions are targeted to different interests. However, we know these categories overlap. For example, scientists might also be people affected by health conditions, and vice versa, and engagement or involvement professionals often have prior research experience from postgraduate or postdoctoral positions.

How should I read the report?

The report does not need to be read cover to cover. We begin with a chapter introducing our research before turning to the main body of the report. We encourage you to focus on the chapters that are most relevant to you, or the things that you want to know more about.

We have divided the main body of the report into chapters covering five aspects of involvement that participants in our research highlighted. These focus on:

- **Opening up conversations** about animal research
- Preparing for **site visits**
- Exploring how to **talk about animal models** from different perspectives
- Understanding how **involvement and ethical review processes** are related
- Outlining how **institutions and research cultures** can **better support involvement**

Each chapter is divided into sections for people affected by health conditions, for scientists, and for involvement and engagement practitioners. You might want to start with the section most relevant for you. You may also want to explore perspectives from other participants to understand more about their views.

Doing involvement is primarily about building relationships between people with different expertise and creating opportunities for meaningful learning and exchange, so we warmly welcome comments and further questions on any part of our research (see contact details on [page 1](#)).



1.4 References and further resources on involvement in laboratory based research

- Hanley, B (2019). Patient and public involvement in laboratory-based research: reflections on six studies. Available at: <https://tinyurl.com/k5y55zk3>
Bec Hanley and colleagues explore patient and public involvement (PPI) in six laboratory-based research studies, across three organisations. This report outlines how PPI adds value to laboratory based researchers. It can motivate researchers, but training and support are required, and the report calls for it to be a funding requirement. They identify several anticipated challenges around involvement in laboratory based research, including terminology, health, and communication, which can be improved to better support PPI.
- NIHR (2021). Supporting Patient and Public Involvement in research. Available at: <https://tinyurl.com/yt74u3mc>
The NIHR (2021) have relaunched their key guidance for patient and public involvement. These resources are aimed at researchers, involvement and engagement professionals, and patients, carers and publics. You can browse these resources [here](#).
- NIHR's 'Centre for Engagement and Dissemination' have guidance resources across involvement and engagement. These include aspects such as paying contributors and good practice guides. Information about this can be found [here](#) – <https://tinyurl.com/mr39seza>
- Parkinson's UK (2020). A practical guide to patient and public involvement in laboratory research. Available at: <https://tinyurl.com/37e77h8z>
This website contains practical guidance on how to involve patients and publics in laboratory research. There is a helpful section on this webpage about involving people with laboratory research during the pandemic. Many other medical charities now have guides to involvement in their work online and we would encourage you to explore the organisation most relevant to your experience or work.
- The **Shared learning group** have produced several guidance and recommendation documents. They aim to encourage shared learning between voluntary sector organisations in the UK. They look at involvement across all areas of work.
Available at: <https://tinyurl.com/5yaxfba6>
- Stewart, D (2018) 'Involving Patient, Families and Public in Pre-Clinical or Non-Clinical Research – Useful Sources of Information'. Available at: <https://tinyurl.com/3bwctdyb>
Derek Stewart has collated a [list of resources](#) around involvement and preclinical research. This includes academic resources, videos, guidance documents, standards and recommendations across industry.

2

BACKGROUND RESEARCH

2. BACKGROUND RESEARCH

2.1 The Animal Research Nexus Programme

This report is based on research carried out as part of a Wellcome Trust Collaborative Award on The Animal Research Nexus (2017-2023). This programme of work looked at connections between scientific and social processes across animal research. Researchers at the University of Exeter traced the ways that people affected by health conditions were involved in conversations about the use of animals within biomedical research and considered how more inclusive and meaningful dialogue could be supported. The involvement literature uses the idea of a meaningful conversation to indicate one in which people feel seen and heard in the way that is appropriate for them.

How did we do this research?

The work was carried out by Prof Gail Davies and Dr Richard Gorman. We attended and observed a range of engagement and involvement activities, including patient involvement forums, 'patient open days' at laboratories, and specially organised visits to research facilities. We carried out two targeted recruitment surveys. One focused on people affected by health conditions who were involved in work for a medical charity (n=27), and one was completed by research scientists who were working across a range of different health conditions (n=25). We then carried out 59 interviews (2018-2020) with approximately equal numbers of people affected by health conditions, research scientists using animals in their work, and engagement and involvement practitioners working for charities and research institutions. All people taking part in our research were offered anonymity, so any names used here are fictitious.

We also organised two workshops. One in 2018 provided an opportunity for people involved in research and sitting on ethical review panels to talk about their roles and exchange experiences. A further workshop in 2019 included people affected by health conditions, lay members of ethical review panels, researchers, and involvement and engagement practitioners. Our analysis of the surveys, interviews, and workshops focused on understanding what involvement might mean, and achieve, for different people. Outputs from the workshop included the practical resources and recommendations that different people felt would help them have more meaningful conversations about animal research in this context. Dr Gabrielle King worked with the team on integrating these into this report.

2.2 Understanding different perspectives

We wrote up the qualitative analysis from this research in our interim report (Gorman and Davies, 2019 – you can find a link to this report on [page 17](#)). This analysis demonstrated that:

- Many **people affected by health conditions** see value in conversations about animal research, whether these take place within engagement or involvement processes. Many felt these encounters helped inform their involvement activities and alleviated anxieties and concerns. However, many questioned how far they were listened to. For some, involvement around animal research is an ethical and emotional challenge.
- For **scientific researchers** using animals, involvement can be an opportunity to engage people's lived experience to improve the relevance of research for people affected by health conditions. However, there is not much experience of having conversations about animal research during involvement processes and many identified challenges in moving from an emphasis on research dissemination to two-way communication in involvement processes.
- Many **funders and organisations** believe people affected by health conditions can, and should, be involved with all types of research. However, many were apprehensive about managing public concerns around animal research, and unsure when and whether these conversations made a meaningful difference to research. Many initiatives involving people affected by health conditions in conversations around animal research were motivated by seeking public support for animal research, rather than shaping research to reflect the views of those affected by health conditions.

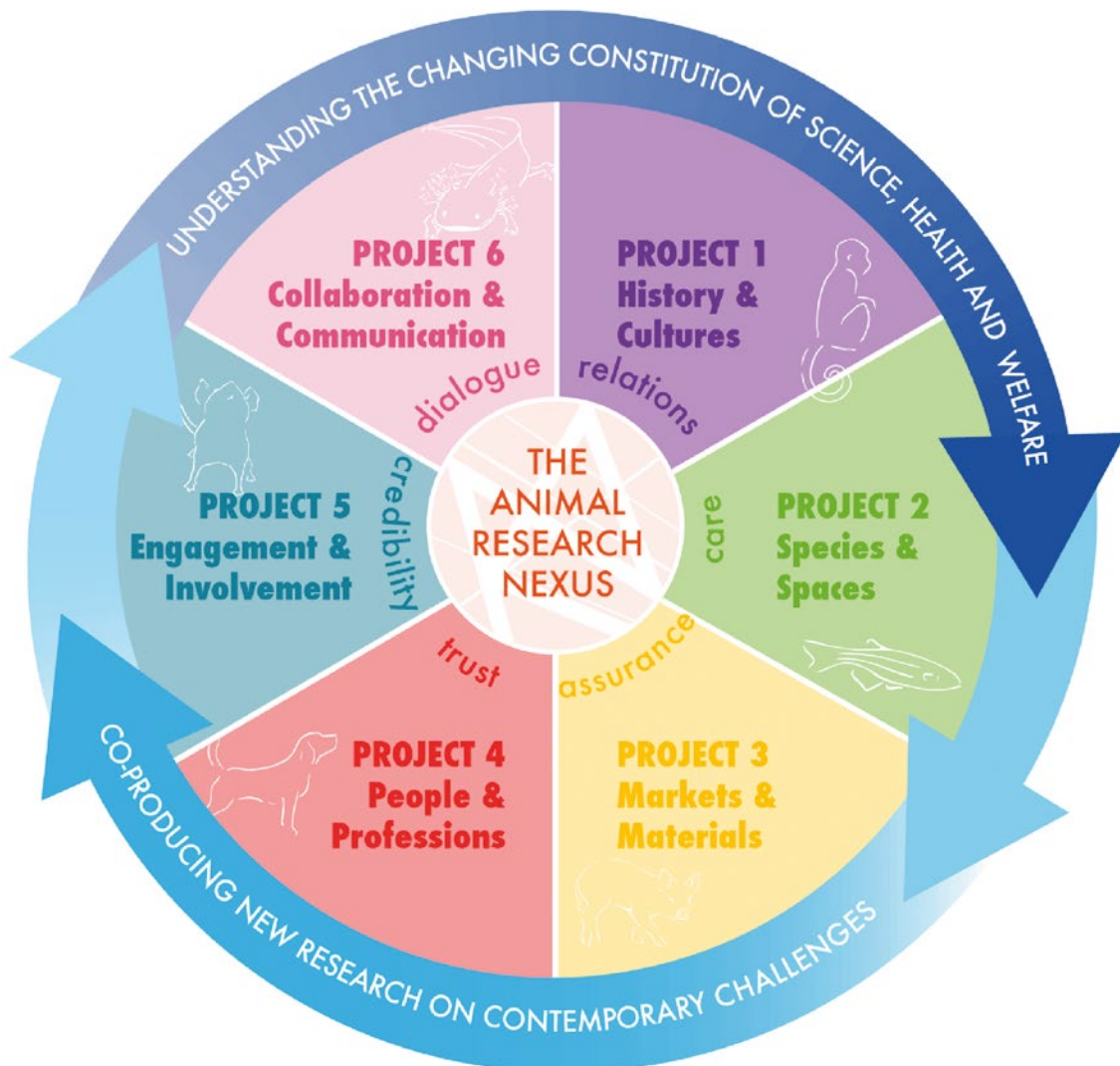
2.3 Generating new conversations

As well as documenting the different perspectives and challenges with involvement around animal research, we used our analysis to identify the potential for generating new conversations around the following common interests.

The majority of people we spoke to thought there were **new opportunities** to integrate involvement with people affected by health conditions and talked about how these might be related to the **growing openness agenda** around animal research. All groups were interested in talking about how **decision making in research** happens, particularly around how the focus of research is decided and how it related to ethical review. All talked about the importance of discussing **timescales to translation** openly and honestly, including understanding more about the role of animal models in research. Finally, all groups wanted to consider how **silos structures** in research could be addressed.

Understanding the differences between perspectives can help make these conversations more productive. For example, people affected by health conditions often talked about health in terms of narratives, whereas scientists talked about experimental protocols. These may touch on similar and important issues, but the different languages can be a barrier to communication. We suggest these differences can help identify where **further reflection and training** may be needed to support two-way exchanges.

In what follows, we use insights from this analysis to look at the opportunities that come from developing conversations around animal research. We discuss the practical steps needed to help different groups communicate when they don't use the same language and introduce some areas (including animal models and review processes) where further technical information is likely to help inform conversations across different positions.



The Animal Research Nexus Programme brought together researchers working on the social and historical dimensions of animal research through six interrelated projects (see <https://animalresearchnexus.org/>). Project 5 at the University of Exeter focused on patient engagement and involvement.

2.4 References and further resources on involvement and engagement from the Animal Research Nexus Project

- Davies, G., Gorman, R., McGlacken, R., and Peres, S. (2021) 'The social aspects of genome editing: publics as stakeholders, populations and participants in animal research', *Laboratory Animals*. doi: [10.1177/0023677221993157](https://doi.org/10.1177/0023677221993157).
This academic article explores the different roles that publics play in contributing to debates around genome editing, including as people affected by health conditions.
- Gorman R & Davies G (2019) Patient and Public Involvement and Engagement (PPIE) with Animal Research. <https://tinyurl.com/4ez8vcxb>
This interim report from the Animal Research Nexus Project presents qualitative research outlining the different perspectives involved in conversations around animal research.
- Gorman, R. and Davies, G. (2020) When 'cultures of care' meet: Entanglements and accountabilities at the intersection of animal research and patient involvement in the UK, *Social and Cultural Geography* <https://doi.org/10.1080/14649365.2020.1814850>.
This academic article reviews the growing emphasis on a culture of care in clinical and animal research.
- We have also been working on a training resource that aims to help people working in research think through the first steps of incorporating careful patient engagement around animal research. The workshop is based on discussion of a script of a fictitious scenario that brings together different perspectives of scientists, animal technicians and people affected by health conditions. Please contact Prof Gail Davies for a copy, or for more information (G.F.Davies@exeter.ac.uk).





3

OPENING UP CONVERSATIONS ABOUT ANIMAL RESEARCH

3. OPENING UP CONVERSATIONS ABOUT ANIMAL RESEARCH

Read this chapter if you want to know more about starting conversations about animal research, where you might encounter conversations around animal research, and what support is available to help you to navigate this.

3.1 Key Points

- Good involvement and good engagement are often linked. Being open about animal research is important for building two-way dialogue and trusted relationships
- Talking about animal research can be tricky, but having questions and concerns about what happens can also be difficult for many people affected by health conditions
- The freedom to choose whether or not to be involved in conversations about animal research is important for people affected by health conditions

3.2 Openness, engagement, and involvement

Starting conversations

It can be difficult to know how to start a meaningful conversation about research involving animals. Our work found that good involvement (carrying out research in active partnership with people) often starts with good engagement (activities based around sharing knowledge), through getting to know people, facilitating two-way exchange about research, and building up relationships. In the case of animal research, starting to have these conversations can be particularly important, but also potentially challenging, because of sector-wide moves towards openness after a long period of not talking about animal research.

Openness in Animal Research

The move towards greater openness has been marked out by the **Concordat on Openness on Animal Research** in the UK. This provides incentives, resources, and support to help scientists and organisations become more open about animal research. Many organisations have signed the Concordat, making a set of commitments towards talking more openly with different public groups. If you work in the UK, it is likely that you will be working for or with one of these organisations. The Concordat focuses on communications with the public in general, but there is also a gap because it is not explicitly aimed at building two-way dialogue with people affected by health conditions.

Our work, and the work of others in this area, suggests that building relationships between scientists, practitioners, and groups affected by health conditions is key. This doesn't need to be formal but might just begin with encountering people and perspectives. Below are some recommendations for each group starting the early stages of building conversations.

3.3 For people affected by health conditions

Many conversations about animal research begin at public events like open days, science festivals, and organised engagement events for people affected by health conditions. Discussion about animal research may also arise in involvement activities, like scoring research grants at a review panel run by a medical research charity. We have put engagement and involvement events together here as both are places where people may find themselves thinking and talking about animal research with scientists for the first time.

Do I have to be involved in conversations about animal research?

Everyone has a different perspective on these encounters. Many people we spoke to did value finding out more about animal research on the condition that affected them. However, not everyone expects to, nor wants to, hear about animal research. Every perspective is important, even if for you, it is about sharing uncertainties and concerns, and then stepping away. The scientists and event organisers that you speak to are also likely to have a wide range of views on the topic of animal research. Some might relate to your feelings and concerns.

Reflections from our research

"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."

Tabitha, a patient representative who has been involved in research for over 5 years

"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, a patient representative who has been involved in research for over a year

What if I want to know more?

The increasing openness around animal research means you may be able to find information about animal research on organisational websites. You can also ask organisers and scientists at any point during events. Researchers and involvement practitioners should be willing and prepared to answer your questions.

Reflections from our research

“Most people’s concern would be around how it’s taking place, and how the animals are being treated, what the effects are on them, and what their care is like.”

Rebecca, an involvement and engagement practitioner at a medical research charity

Scientists are also increasingly involving people in the research that affects them. This means you might want to ask what opportunities exist for involvement, including around animal research. Many scientists we spoke to wanted to be more open about animal research and valued making these connections with people affected by health conditions but recognised there was still a lack of experience in having these conversations. If you have thoughts about how these conversations would work for you, these are likely to be useful for scientists too.

3.4 For researchers and scientists

There is no single right way to start having more open conversations with people affected by health conditions about animal research. Involvement is increasingly required by funders of laboratory-based research. However, most organisations are still focused on disseminating information about animal research to the public, rather than facilitating conversations with people about research involving animals.

How can I start to engage people with my research?

You could start by presenting your work at public events like open days, science festivals, or research stalls. These offer opportunities to develop confidence in talking to people about animal research. Many people we spoke to found they had built experience and confidence from engagement events, which led them to incorporate more involvement within their research.

Where can I get support to do this?

- If your organisation, team or department has an **involvement and engagement officer**, you should find it helpful to contact them. They will be able to help you develop engagement and involvement activities in which people's contributions are valued. They may be able to help you find peer support, including attending your first event with someone who has more experience, or provide opportunities to debrief with other researchers afterwards.
- You are also likely to find it helpful to talk to the **Named Information Officer** at your establishment, which is an organisational role required under ASPA. They are primarily responsible for ensuring that staff within the establishment have access to species-specific information about the animals housed and procedures undertaken. They should also have information around Home Office licensing and the role and tasks of the AWERB. They should be able to provide you with information about the scope and scale of animal research at your institution.
- If your organisation has a **press office**, they are likely to have experience in managing communications and may be able to help you prepare for conversations, including sharing the kinds of questions they have been asked in the past. **Understanding Animal Research** also provide a list of commonly asked questions aimed at supporting media communications.
- Peer networks with **other colleagues** can offer support and the opportunities to exchange practical tips and experiences.
- **Research charities and charities linked to the health condition** you are researching may have resources around involving people in research or working with the particular condition more generally.

All of these people will have useful expertise, but they may also have different views on when and where conversations should take place. Being clear about why you are involving people in research can help you to decide when you should talk to people. However, it is most helpful to talk to people as early as possible because they may have suggestions that can shape the trajectory of research, including highlighting the symptoms that are most important for their quality of life, or indicating issues around their clinical experience that might enable your research to move more easily from experiments on animals into clinical trials.

Reflections from our research

Robb, a senior research scientist at a university, found that asking questions helped him to involve people in research. He asked a support group of people affected by a condition if he could send them some documents about his research, to share out and to give feedback. He explained what he thought was important in understanding the progression of the disease, how he had been thinking about disseminating the data, and asking an open question of what they thought. They came back with comments on the complexity of the lay summary and supported the research question. They also challenged him to think differently about disseminating the data to include drug companies that play an important role in the disease community.

3.5 For involvement and engagement practitioners

As involvement and engagement practitioners, talking about animal research and supporting these specific conversations might not have been part of your training or role so far.

You might find it helpful to familiarise yourself with your organisation's stance on openness and explore how they talk about animal research. Many universities have commonly asked questions and statistics that can be downloaded indicating the number of animals used in medical research. Organisations like the RSPCA and Understanding Animal Research also have a range of useful resources on their website. We list these at the end of this chapter.

What sort of support can I provide?

It is likely that scientists will come to you for advice and support. You might also be the person responding to, and in contact with, people affected by health conditions. You might be able to support these conversations by:

- **Signposting** people to the relevant existing resources on involvement and openness on animal research (see [section 3.6](#) for some suggestions).
- Setting up **peer support groups** around public and patient involvement for scientists, where they can talk about issues, concerns, and ask for advice from other colleagues.
- Helping **build networks** between organisations, others in similar roles, and charities.
- **Identifying and developing training** that supports more open conversations across the diversity of perspectives about animal research.

It can also be helpful to emphasise that agreeing to be involved in one project does not mean that people affected by health conditions will want to be involved in other projects. People need to know that stepping away and choosing not to be part of conversations about animal research will not stop them taking part in future involvement work. Being open can also mean being open about your own questions, uncertainties and concerns as you start having these conversations. You are not expected to know all the answers.

3.6 References and further resources on starting conversations around animal research

- Cowan, K (2018). Can patients be involved in preclinical research? In BMJ Open Blogs. Available at: <https://tinyurl.com/2e4zk68h>
Katherine Cowan has written a short piece on beginning and undertaking involvement in preclinical research. The includes examples of scientists doing involvement, what it offers, and some of the challenges that need to be navigated.
- Gorman, R and Davies, G (2019). Patient and public involvement and engagement (PPIE) with animal research. Available at: <https://tinyurl.com/usnnm64b>
Gorman and Davies (2019) outline the different expectations people have of Patient and Public involvement and Engagement with animal research. In this they review the opportunities and challenges across perspectives. They also identify preliminary recommendations for enabling more meaningful involvement.
- Ormandy, E.H., Weary, D.M., Cvek, K., Fisher, M., Herrmann, K., Hobson-West, P., McDonald, M., Milsom, W., Rose, M., Rowan, A. and Zurlo, J., 2019. Animal Research, Accountability, Openness and Public Engagement: Report from an International Expert Forum. *Animals*, 9(9). Available at: <https://www.mdpi.com/2076-2615/9/9/622>
This academic paper discusses a forum between academics and policy experts. It sets out current governance practices regarding openness and transparency of animal research, and outlines some of the difficulties which arise when balancing openness, confidentiality and public engagement.
- Several relevant charities and research support organisations can offer support (often to those they fund). It might be worth looking at the relevant disease-related charity's website to see whether they have pre-existing resources.
- You can also read more about the **Concordat on Openness on Animal Research**. Their website contains several reports, a list of signatories and what the commitments mean in practice.

4

PLACING DIALOGUES ABOUT ANIMAL RESEARCH

4. PLACING DIALOGUES ABOUT ANIMAL RESEARCH

Read this chapter if you want to know more about visiting or inviting people into animal research facilities. Scientists and engagement and involvement professionals need to consider issues around accessibility and the emotional aspects of research when inviting people into facilities or doing involvement online. People affected by health conditions might find it helpful to ask certain questions before taking part in a laboratory tour.

4.1 Key Points

- Involvement and engagement can take place in several different locations. In the case of animal research this includes research facilities.
- There are practical issues that need to be considered when deciding where to hold events and activities. These discussions should listen to the needs of people affected by health conditions.
- Conversations might also take place virtually. Virtual involvement and engagement can help with accessibility. However, it can also pose different challenges, such as providing emotional support over the phone, and having to have conversations about animal research in one's own home.

4.2 Preparing to visit an animal facility

People affected by health conditions (usually those who are involved in review processes), are often invited into research facilities or laboratories for tours or for meetings. Sometimes this is recommended on the basis of being able to see the sorts of work they might be commenting on in grant or ethical reviews, and how it is undertaken. We cover these reviews in more detail in [chapter 5](#) and [6](#).



Preparing resources

Several resources already exist for preparing people to come to events at research facilities or in laboratories. These resources are for those invited to visit animal research facilities, or members of the public sitting on ethical review panels. Please see [section 4.7](#) for further links.

The RSPCA offers [guidance](#) to those coming into research facilities, aimed at helping members of AWERBs to prepare. They provide a series of recommendations and suggestions of things to do before visiting animal research facilities. This includes questions that you might want to ask about the animals, and what you might want to look out for, such as opportunities for discussion, and how staff behave and interact with animals.

Lab Animal Tours is a digital tool which allows people to take 360° tours of four animal research facilities: the [University of Bristol](#), [University of Oxford](#), [Mary Lyon Centre at the MRC Harwell](#), and [The Pirbright Institute](#). It shows how animals are housed, what laboratory settings look like, and provides further information on the kinds of research that are done there.

Below, we set out some of the different questions and considerations that you might have when it comes to visiting a facility or organising involvement and engagement activities where animals are used in research.

4.3 For people affected by health conditions

Where am I going?

Being involved in conversations about animal research can include going to new places. This might include research facilities where you see the animals and science in practice. Our research found that this can be valuable for getting insight into how things happen and what they look like. It can also help with reviewing grants or commenting on research.

Reflections from our research

Rachel, a patient representative who took part in our research, is a former civil servant. She came to be involved in research over five years ago, when she was sitting in the waiting room at one of her husband's appointments. One of the magazines there had information about a patient involvement network for people who were affected by neurological conditions. She started volunteering to be involved in reviewing research. Being able to visit and be shown around different spaces helped to get a basic understanding of what researchers were doing, that she could bring back to her own reviews. By seeing what people are trying to achieve, Rachel also feels that she makes connections more easily between the science that she reads about, and her experience as a family member and carer.

If you have not previously been to facilities, or you are uncertain about what you might see, it might be helpful to visit the online resources in the [section above](#).

What might I find it helpful to know?

Coming to research facilities and laboratories, particularly if you haven't visited before, can be daunting. Below are some questions that you could ask the person organising the event.

Access:

- How accessible is the location?
- Where are transport links or parking?
- What accessible facilities are available?
- Are there chairs and rest points?
- Is there anything in particular I need to know about?
- *When coming to research facilities, you might also need to cross sanitation barriers (like air showers) or might go to places with temperature changes. The person organising an event should raise these in advance, but if these are relevant to you, ask for more information or discuss what might accommodate your needs in these circumstances.*

Preparation:

- What resources can I look at, or share with others, to prepare me?
- Are there other people who have been before that I can talk to about the questions I might have?

Debriefing:

- What happens if I find the conversation difficult?
- Is there somewhere I can go to step away for a while, or to leave easily?
- Will there be opportunities for debriefing about what the research has talked about if it is necessary?
- Are there going to be opportunities for rest? Scientists should build in rest breaks and opportunities to debrief (as a group, or individually) when planning involvement.

4.4 For researchers and scientists

Bringing people affected by health conditions into research facilities can offer opportunities for people to see what goes on in animal research. This can be helpful for people affected by health conditions, as a way of seeing and talking to people about what they are reading about or commenting on in reviews and research proposals. It can also enable you and colleagues to connect the research with the lived condition, and to see the reason that you are doing this work.

Being clear about why and where:

It is important to communicate to attendees about why you are holding this tour or having an event, so that people know what to expect. The reason could be the opportunity to see research in practice or to connect the research to the lived condition. It is also important to be openly transparent around the expertise in your institution. Research scientists who focus on the preclinical aspects of the disease are not likely to be clinicians with a detailed knowledge of clinical symptoms or living with the condition. Coming into animal research facilities is also not for everyone. It is important to make it clear that not wanting to come will not prevent people from being involved in conversations about animal research or commenting on reviews.

What might I need to consider?

There are some things that you can do to make it easier for people affected by health conditions to visit (or to decide to visit) research facilities. The list in [section 4.3](#) contains some questions which you should consider in advance of events and ensure you have communicated either to the person organising the event or, if this is you, to attendees. There is no single method which will be appropriate for everyone affected by health conditions. You should ask people in advance about their needs and contact the relevant research charities who are likely to have information that can support you in planning carefully.

Additional considerations:

When thinking about bringing people together, you need to consider things like cost, which you might need to discuss with your colleagues. It is considered good practice to offer payment for expenses (such as travel to research facilities). There are also growing conversations across wider involvement community around paying people for their time and contributions. This might be more relevant to longitudinal work, such as grant reviewing ([chapter 5](#)). You can find more information about budgeting for involvement, including a cost calculator on the archived Involve website [here](#).

Reflections from our research

“When you’re dealing with people with movement disorders, you have to think about access and everything else very carefully, but also just the logistics. People with [health 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.”

Robb, a senior scientist at a university.

4.5 For engagement and involvement practitioners

What do I need to know?

If you are organising events at places like animal research facilities, you should consider the questions in [section 4.3](#), and provide relevant and appropriate information to attendees (and your research colleagues) in advance. This should include asking people what they need. It might also include providing accessibility information, including where people can park, how far away this is from the entrance, whether there are steps, ramps, or protruding door thresholds that might be difficult for people with mobility issues. These should also set out what to expect when taking a tour of the facility such as needing to pass through air showers, whether there are temperature changes, and where accessible facilities are. You could also include links to resources like the 'Lab Animal Tours' website, to show people what facilities are like, and to encourage them to discuss any additional requirements they might have to make venues or events accessible to them.

Who else should I ask?

There is no single aim or approach to organising a visit to a research facility, and people affected by health conditions may have different needs. You should also make sure that scientists and anyone else involved in the event is aware of any needs to consider.

4.6 Virtual involvement

Is virtual involvement suitable for me?

Virtual involvement means people are not required to travel to spaces that are often hard to access via public transport (like animal research facilities). Not needing to travel can increase physical accessibility and there are lots of reasons why virtual might be a popular option. However, virtual involvement means conversations and encounters can impact the way that relationships are built and the opportunities for informal conversations. There are fewer opportunities for individual coffee chats or informal conversations with the person sitting close by. This emphasises the importance of providing debriefing opportunities through group discussions as well as individually. Conversations also extend into spaces where people are living or working. Not everyone will feel comfortable showing where they are, which can often feel personal. You might find it helpful to offer information about blurring backgrounds and provide options to keep cameras off.

Virtual involvement

Several research charities have provided guidance for planning and undertaking virtual involvement and engagement. The Research Design Service (part of the NIHR) have produced [guidance](#) on costing, organising, and recording online involvement events and activities. Parkinson's UK and others have put together advice on doing [PPI in the pandemic](#). Please see resources on [section 4.7](#).

4.7 References and further resources on the placing and places of patient involvement

- Association of Medical Research Charities (2020). Public Involvement and Engagement in research during the Covid-19 pandemic. Available at: <https://tinyurl.com/y6kn93k3>
*The Association of Medical Research Charities have produced this **report** on the challenges, priorities and opportunities for involvement in the COVID-19 pandemic.*
- Lab Animal Tours. Available at: <https://www.labanimaltour.org>
Lab Animal Tours is a digital tool which allows people to take 360° tours of four animal research facilities shows how animals are housed, what laboratory settings look like, and provides further information on the kinds of research that are done there.
- Parkinson's UK et al (2020). PPI in the Pandemic. Available at: <https://tinyurl.com/any3enyu>
Parkinson's UK, Alzheimer's Society, the NIHR and other members of the Shared Learning Group have put together a series of information and recommendations for doing PPI in the Covid-19 pandemic.
- Research Design Service (part of the NIHR) have produced guidance on costing, organising, and recording online involvement events and activities. This is available at: <https://tinyurl.com/4d4x8x45>
- RSPCA (2020). 'Visiting the animal unit'. Available at: <https://tinyurl.com/3ba5335x>
*This **guidance** is aimed at helping members of AVERBS to prepare to visit research facilities. They provide a series of recommendations and suggestions of things to do before visiting animal research facilities, some of which are likely to be valuable for people affected by health conditions visiting in general. This includes questions that you might want to ask about how animals are being cared for.*



5

TALKING ABOUT ANIMAL MODELS



5. TALKING ABOUT ANIMAL MODELS

Read this chapter if you want to understand more about involvement and animal models. We outline how people affected by health conditions can contribute to discussions around animal models, how scientists can recognise and use this to enhance their research, and how scientists and engagement and involvement professionals can support these conversations.

5.1 Key Points

- Opening up discussions about animal models can be one way for the lived experience of people affected by health conditions to inform research.
- Researchers need to be open to the idea of changing their research if involvement is to have a meaningful impact.
- Care is needed to ensure involvement processes do not convey information about the progression of the disease in animals that would not already be known to people who are involved at that point.

5.2 What is an animal model?

If you have been to a scientific talk or event, reviewed a grant or ethical application, or been involved in conversations about projects using animals in research, you are likely to have heard discussions about animal models. The term 'animal model' refers to animals used in scientific procedures to model certain aspects of human disease. Animal models can be used to look at things like disease pathways, predictive biomarkers, genetic and environmental interactions, and drug responses. Data obtained from animals is usually only one part of the larger picture and is often combined with other research or clinical data.

Using animal models in research

Animal models are used in different ways when researching biological processes and testing new drugs. Researchers are not permitted to use animals in research if there are feasible, valid alternative methods to answer the scientific question. Sometimes the animals and experimental protocols that need to be used are set by regulators, for example, in standard tests for the safety and efficacy of new drugs for licensing purposes. However, often research scientists will be selecting from a wide range of animal models from which to research biological processes and potential drug treatments.

How are animal models chosen?

When selecting which animal model to use, scientific researchers will be guided by their research questions, the previous research in the area, what is most practical and ethical, and the way they intend their research to be translated into other contexts, like future clinical trials.

Although conversations around animal models can be both technical and sensitive, people affected by health conditions have relevant experience to contribute. People affected by health conditions will know what research questions are most important to them. They may also have experience of being involved in similar projects and have perspectives that can help research translation.

Reflections from our research

Our research showed that many people affected by health conditions did have views about animal models, though others were uncertain about when animal models were useful for research. We also found that scientists were unsure how people affected by health conditions could add to scientific discussions about animal models.

5.3 For people affected by health conditions

What can I add to discussions about animal models?

You have knowledge and experiences that are valuable to choosing and using animal models. For example, you might know about a particular symptom which would affect how a drug is administered. You may have reviewed earlier projects which enable you to contribute to complex conversations about developing animal models, but you don't need to have any prior knowledge about science to make useful contributions. This section is about how you can use what you know to contribute to conversations and questions about animal models.

What questions could I ask?

If you are reviewing projects which include animal models you may want to reflect upon the following questions, or pose them to applicants in your response:

- **Relevance** How effectively does the research proposal explain why a particular animal model is being used? Is the researcher clear about precisely how they are using an animal model to understand human health conditions? How many people affected by a health condition is this specific animal model relevant for? Does the experiment seem to be using the animal model to focus on the health aspects most relevant to you and others? What other kinds of models, animal or non-animal have they considered when selecting this as the best model for this kind of research?

- **Translatability** Does the researcher explain what it could take for this research to translate into human clinical trials? Are there things from your own experiences that you think scientific researchers might find it helpful to know, for example around how you normally use treatments, or how other parts of research and care are organised?
- **Track record** You might find it interesting to ask how successful this scientist, and others, feel they have been in using this particular animal model? What does the proposal say about their track record or their collaborations with others? Do they explain how they will make their data or animal models available to other researchers to use?

You may also want to ask those organising the involvement about how they intend to use your comments on this specific aspect of the research and whether you will get feedback on your questions.

Reflections from our research

In our research, we found that people reviewing biomedical research proposals had a lot to contribute. People raised a series of issues around whether alternatives could be used, why there were issues translating research from animals to people, and how research models might be improved. The main comments raised by people affected by health conditions about animal models were about the relevance of models to the human experience of the disease, the issues with translating animal studies to clinical contexts, and the length of time taken to develop better models. However they rarely received answers to these questions, which they found frustrating.

"I tend to question quite avidly, why would a mouse model be useful in this particular situation? Why can't the researchers be looking for an alternative model, maybe a stem cell? So that might be some of the feedback I give quite often."

Tina, a patient representative who has been involved in research for over 3 years



5.4 For researchers and scientists

What can involving people add to my work?

While decisions around research priorities and animal models can be tricky for people outside of an area of speciality, people affected by health conditions can still contribute.

Section 5.3 above contains a list of questions around research relevance and translatability that people affected by health conditions might ask. When involvement happens early in the research process, these questions may help build a meaningful conversation between the experience of illness and development of new experimental protocols that increases the relevance of research.

For this reason, it is important to start to talk to people affected by health conditions before you submit the project for review, where possible. This can help to ensure it is communicated clearly and to test the reception to the research.

Reflections from our research

When asked what might motivate them to use patient involvement in the future, the scientists we spoke to said that the most important factor was the opportunity to increase research relevance. However, creating opportunities for people affected by health conditions to shape the research relevance can mean opening up some complex conversations, like the choice of animal models.

Scarlett, a research scientist at a university who we spoke to as part of our research started going to patient groups when she was putting together a fellowship application. She developed a way of asking people questions about animal models on their terms. This involved telling people about the research that she had already done, and asking people comments about whether they needed more information, whether they had any questions they would prefer, or whether there was a scenario they had not yet thought of. However, when reflecting on her experience, Scarlett suggested that she might still be in the minority in enabling involvement to impact her research:

"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."

5.5 For involvement and engagement practitioners

Engagement and involvement professionals have an important role to play in connecting people affected by health conditions in conversations with research scientists.

How can I support people to have conversations which are supportive and meaningful for them?

As involvement and engagement practitioners there are several things that you might do. This includes:

- Talking to research scientists and people affected by health conditions about the **most appropriate time for these conversations to take place** in the research process so that they can have a meaningful impact on research relevance.
- **Collating examples of good practice** and case studies of where involvement has had benefits for your researchers or research area.
- **Developing briefing materials** to help both research scientists and people affected by health conditions to have a meaningful exchange around animal models that inform the research and encompass people's lived experience. We have made some suggestions in [Section 5.3](#) which may help your preparation.
- Ensuring that everyone is **aware of the potential for discussion of animal models to touch on the medical experience** of people affected by health conditions. This connection underlines the value of including the experiences of people affected by health conditions.



Reflections from our research

Some of the involvement and engagement practitioners that we spoke to recognise the importance of including people affected by health conditions in the conversations about animal models.

However, **Sian**, a senior scientist at a university also spoke to us about how discussions of disease trajectories have ethical dimensions. Conversations could disclose parts of a condition that people were not yet aware of. It can be helpful to remind scientists and those undertaking involvement activities of the need to be careful around these issues. She explained:

"If you invite [people affected by a health condition] to an event and you tell them about stuff, and you've got no support in place that's a risk. You start talking about "this happens, and this happens" and you talk about the way the animals die, they will take that home and keep that with them. There is a potential to cause harm through involvement, which isn't meant to cause harm but you're sharing information, you're having those open discussions, then you risk revealing stuff that neurologists and consultants haven't got round to telling them yet"

Sian, a senior scientist at a university

Generating opportunities for people affected by health conditions and scientists to talk about animal models is complex because it involves technical questions, sensitive issues around animal experiences, and people's expectations around future health. However, these conversations are important. All participants in our research talked about the growing challenges around translating animal research into clinical treatments, indicating the value of bringing people into meaningful conversations that can build relationships, foster responsible research, and generate new ideas.



5.6 References and further resources on translational research and animal models

- Lawler, M., Alsina, D., Adams, R.A., et al 2018. Critical research gaps and recommendations to inform research prioritisation for more effective prevention and improved outcomes in colorectal cancer. *Gut*, 67, pp.179-193. Available at: <https://tinyurl.com/mpd9mhx3>
This academic paper sets out how research gaps can inform research prioritisation. Part of the process that Lawler and colleagues describe involves discussions of the need to develop 'animal models with greater resemblance to humans'. The paper contains some detailed scientific information around colorectal cancer research which will not be relevant to everyone, but for those involved in other kinds of research, it sets out a detailed process of identifying research gaps and using these to shape recommendations (see, for example, the flow diagram on page 180).
- Lowe, J.W., Leonelli, S. and Davies, G. 2020. Training to translate: understanding and informing translational animal research in pre-clinical pharmacology. *TECNOSCIENZA: Italian Journal of Science & Technology Studies*, 10(2), pp.5-30. Available at: <http://www.tecnoscienza.net/index.php/tsj/article/view/391>
This academic article reports findings from interviews with researchers in pharmacology who are looking at ways to improve the translation of animal research, including practical ways of better connecting animal experiments to clinical trials and patient experiences.
- NC3Rs 'The 3R's', available at: <https://nc3rs.org.uk/the-3rs>
The NC3Rs is the UK's national organisation for the 3Rs. This webpage set out the principles 3R's and what this means in practice for animal models.
- The National Academics of Science, Engineering & Medicine 2015. Reproducibility Issues in Research with Animals and Animal Models. Available at: <https://tinyurl.com/2dteu5zr>
This web page outlines reproducibility issues in animal research and research with animal models. It is drawn from a workshop in which researchers from around the world explored what could lead to irreproducible results. The website particularly effectively splits the challenges into different parts of study design and provides some criteria for judging published scientific reports.
- van der Worp H.B., Howells D.W., Sena E.S., Porritt M.J., Rewell S., O'Collins V, et al. 2010. Can Animal Models of Disease Reliably Inform Human Studies? *PLoS Med* 7(3): e1000245. <https://doi.org/10.1371/journal.pmed.1000245>.
Through this academic paper, van der Worp and colleagues discuss some of the challenges and reasons for translational failures when it comes to animal research. The paper explores these through discussing internal and external validity and provides recommendations for reporting aspects of study quality.

6

CONSIDERING ETHICAL REVIEW

6. CONSIDERING ETHICAL REVIEW

Read this chapter if you want to understand how grant review and ethical review processes are related when research involves animal research, and how involving people with health conditions can help to enhance the potential relevance and value of the research in both.

6.1 Key Points

- Ethical review, including weighing the harms and benefits of research, is required before any regulated scientific procedures are carried out on animals in the UK.
- Animal Welfare and Ethical Review Bodies may include lay members who can contribute to ethical review, but they are not specifically asked to represent people affected by health conditions. AWERBS often have a high workload, so it is important to consider how their work can be supplemented by other kinds of involved and engaged research.
- People affected by health conditions can help enhance the potential benefits of animal research, which is a positive contribution to both grant and ethical review.

6.2 Who reviews animal research funding proposals?

Getting funding for, and permissions to do research and testing on animals requires several different review processes.

- **Grant Review:** The scientific merit of a research proposal will be reviewed as part of the project funding application, which could include review by funders, scientific peers, and people affected by health conditions.
- **Ethical Review:** The ethical aspects of research on animals will be reviewed by the local Animal Welfare and Ethical Review Body (AWERB) and formally appraised by the Home Office, including a harm-benefit analysis.
- **Clinical Trials:** If the research then proceeds to clinical trials, the project will need further ethical review focusing on the ethical implications of the study design for those people taking part in the trials.

All of these review processes may actively seek contributions from patient representatives and the public. People affected by health conditions are increasingly asked to review proposals for laboratory and clinical research as part of the grant application processes. Some AWERBs in the UK include independent (lay) people, who may be members of the public (although they do not 'represent' the public). However, the links between these processes are often unclear.

Reflections from our research

Our research found that people reviewing projects using animals in research from a 'patient perspective' were often uncertain what role they were expected to play when talking about animal research, and how their project review connected with the ethical review required by the Home Office. We suggest this topic needs more discussion when supporting involvement around animal research. Conversations are likely to be more comfortable if everyone understands how processes of grant review and ethical review connect and being clear about who has responsibility for the different review processes.

How do these reviews fit together?

As a scientist, you might be required to undertake all of these review processes. As a person affected by a health condition you may have interests in all of these issues, but your formal role might focus on one of them. As an engagement and involvement professional, you need to consider how to communicate these different processes to everyone and, where appropriate, ensure they can inform each other.

Grant and Ethical Reviews

Grant reviews: Grant reviews are normally related to funding applications for research projects. Grants to fund animal research can be awarded by charities, industry, universities, or UK Research and Innovation (UKRI – an organisation which distributes public funds for research). Funders are interested in the quality of the proposed science, its contribution to knowledge, its potential benefit to stakeholders, and its value for money. Funders may expect ethical issues to be discussed, but most formal ethical review takes place after a grant is awarded. Funders will usually commission reviews from the scientific community and potential research beneficiaries to help them evaluate whether to fund a project. Universities and other bodies may also use processes of internal review to help develop good project proposals.

Ethical review is part of the formal Project Licence Application for animal research (see **Terms used in this report**). Scientists present their project to their local AWERB, who will review the implementation of the 3Rs (replacing, reducing, and refining the use of animals in research), potential harms and benefits, and offer advice. If the AWERB advises the Establishment Licence Holder to support the research, a project licence application is then submitted to the Home Office. This application includes information on the project aims, the species and numbers of animals to be used, and the likely experiences of animals. It will outline how the project is applying the 3Rs and how the welfare and care of animals is organised. The project licence application is formally evaluated by the Home Office, including a harm-benefit analysis, and will only be granted if the potential benefits of the project are judged to outweigh the likely harms to animals.

Even though the grant review and ethical review are separate administrative processes, they do have points of overlap. Realising benefits from animal research is increasingly seen as an ethical issue. The ethical review of research by the Home Office is carried out through doing a harm-benefit analysis, which assesses whether the harm caused to animals can be justified by the expected outcomes, including benefits to people. The involvement of people affected by health conditions can therefore help to support ethical review by ensuring the potential benefits from the proposed scientific research are as strong as possible.

6.3 For people affected by health conditions

You have valuable contributions to make by bringing your knowledge, skills and experiences of a health condition to the table. This can help refine research as we outlined earlier in [chapter 5](#) of this report.

What can I add to grant review processes?

You can make valuable contributions to grant reviews through:

- **knowing about living with a health condition** (including explaining what else is in place to help people with your condition, such as support groups, physiotherapy, and how the benefits of the research would fit with this).
- having **experience of reviewing** past proposals
- **applying skills and knowledge** from careers and wider life.

We identified a series of questions about the relevance, translatability and track record of work using animals (see [Section 5.3](#)) which you might want to ask when you review grants that include the use of animals in research.



What other ethical questions might I want to ask or think about?

Helping to enhance the benefits from research using animals is a valuable contribution that you make to ensuring animal research is ethical. You might also want to find out more about how a project proposes to minimise the harms involved in animal research. Many people who were involved in research that we spoke to valued learning about ethics and care in animal research. However, you are never responsible for the outcome of ethical review.

Below are some suggestions that might help you formulate questions if you want to ask about minimising harms and learn more about what scientists are doing with this aspect of research.

- **3Rs** Scientific researchers will be asked in ethical review how they are applying the 3Rs (referring to the replacement, reduction, and refinement of animal research). You don't have to ask, but you might be interested to ask how they considered alternatives to animal research; where do they look? How do they check they are using the right numbers of animals to get valid results but avoid animals being used unnecessarily? Have they explained how they are using the most refined techniques to do the research, and what is done to improve welfare throughout animals' lives?
- **Animal welfare and care** Some people who review research using animals in involvement processes may want to understand what the animals are likely to experience in experiments and may have questions about animal housing and care. Research facilities have dedicated animal care staff who can answer these questions.

Reflections from our research

In our research, people spoke about their experiences of ethical review. These included opportunities to learn more about how animals are cared for, as well as some of the challenges around responsibility and funding.

"What has been pleasing during that time I've been involved with the network is I've actually had opportunities to understand a lot more about what goes on and the ethics involved, and the procedures and controls involved."

Toby, a patient representative involved in research for over 5 years

6.4 For researchers and scientists

You might have experience of review processes that involve people in grant development and the AWERB reviews of project licence applications that include lay members. It is still relatively uncommon to have a 'patient perspective' as part of AWERB discussions or to have people affected by health conditions involved in ethical conversations around animal research.

As we suggest above, it is important that people affected by health conditions have the conversations about research that are most meaningful for them. These often focus on enhancing the benefits of research, rather than taking on explicit responsibilities for reviewing the ethics of animal research. However, our interviews and workshops suggest that many people involved in research are interested in the ethical aspect of animal research. You may want to consider how research involvement and the work of the AWERB fit together in relation to your research and consider how to empower people to fulfil these roles effectively.

Reflections from our research

Our research suggests that people affected by health conditions can be quite ambivalent about animal research. Some people may not want to talk about animal research and its ethics, but it is also important to listen to the animal welfare and ethical concerns that people affected by health conditions have about animal research. The aim should be to provide information when it is asked for and enable people to voice their feelings in a way that is meaningful for them.

While ethical review processes are never the responsibility of people affected by health conditions, it is also important not to assume that they will not be concerned about ethics. It can therefore be worth making clear how the care and welfare of animals has been accounted for in study design, and about how animals are monitored and taken care of throughout the lifetime of a project.



6.5 For engagement and involvement practitioners

How can I make space for discussion?

As someone who is organising involvement activities, you are likely to have responsibilities for staging events, managing review processes, or chairing meetings. In all of these, you will want to consider how to create a space for discussing ethical issues. This could include:

- **Acknowledging the range of views** that people affected by health conditions may have around animal research.
- **Offering opportunities** for people affected by health conditions to find out the information that matters to them about animal research and care.
- Ensuring people affected by health conditions **do not feel responsible for the outcomes of ethical review** of animal research.
- When appropriate, explaining that inputs into **research relevance could make a valuable contribution to the ethical assessment** that people affected by health conditions can make.

How can I support these discussions?

Much of this will be achieved by creating a supportive space to talk about both the potential of research involvement and different perspectives on the ethics of animal research. Some people talked about having this as part of their involvement training.

Reflections from our research

“So we did address that in training, we want people to be aware of some of these ethical issues and form their own opinions and not be afraid to discuss what those opinions are and provide a safe place and opportunity and respecting each other’s opinions and creating discussion and dialogue around it.”

Sabrina, an involvement and engagement practitioner at a medical research charity

Some universities have lay forums where people on different ethical review boards meet together to discuss their experiences. If your organisation does a lot of work in this area, it may be useful to organise opportunities to exchange views. This could include inviting people involved in research to view the work of the AWERB or have an AWERB member present at a relevant involvement event.

6.6 References and further resources on ethical review

- Davies, G.F., Golledge, H., Hawkins, P., Rowland, A., Smith, J. and Wolfensohn, S., 2017. Review of harm-benefit analysis in the use of animals in research. Available at: <https://tinyurl.com/yc3c53jx>
The Animals in Science Committee is responsible for providing impartial to the UK Government on issues relating to the Animals (Scientific Procedures) Act 1986. The ASC produced this report on the ethical review of animal research in the UK in 2017. It includes discussion of the ethical importance of benefits in harm-benefit analysis, which is a key issue that patient involvement could inform.
- Jennings, M., and Smith, J.A. (2015). A resource book for lay members of ethical review and similar bodies worldwide. Available at: <https://tinyurl.com/yck7a8jd>
Jennings and Smith set out a resource book for lay members involved in ethical review. This is designed to facilitate ethical review work of themselves and their lay members.
- RSPCA (2015). Guiding principles on good practice for Animal Welfare and Ethical Review Bodies. Available at: <https://tinyurl.com/mtntufu5>
*The RSPCA have some helpful resources for supporting lay contributions to AWERBS. This is not focused on people affected by health conditions but is aimed at anyone who might become involved in an ethical review board. These resources include **guidance** to help AWERBS to continue to develop their role, to further the 3R's and a culture of care, and to interpret legislation and guidance.*



7

CONTINUING CONVERSATIONS AROUND INVOLVEMENT

7. CONTINUING CONVERSATIONS AROUND INVOLVEMENT

Read this chapter if you are interested in learning about how research cultures and institutions can generate a more supportive and sustainable environment for research involvement.

7.1 Key points

- Involving people in research is about relationships: from establishing conversations to understanding different needs, to building and supporting enduring relationships between scientists and those affected by health conditions.
- Establishing and investing in relationship building, particularly as scientists and engagement professionals, is key to ensuring that conversations are meaningful to everyone who is involved. It is also about creating an environment where people feel comfortable enough to share their decision to decide not to be involved in conversations about animal research.
- Sustaining these relationships can also be challenging and our research has suggested that this work is not always well supported or recognised within research cultures.

We use this chapter to highlight the ways in which conversations about involvement might continue and be better supported, first, within research cultures, and second, within institutions more widely. Here, we shift from looking at individual roles, to thinking about the roles of institutions and those in senior positions. This is because while everyone has a role to play in supporting conversations about research, and enabling others to do this, responsibility for creating an environment and the resources which sustain this sit with the wider research culture and institution. This chapter is therefore about caring for everyone who is involved.

7.2 Culturing care in research involvement

Being involved in, or organising, conversations about animal research, requires considerable practical and emotional work. Our research suggests this often falls to the individuals organising or attending events and those supporting ongoing relationships. To succeed involvement needs to become part of the broader research culture at an organisation, meaning that everyone has responsibility for enabling involvement, and for supporting those doing it. We suggest that creating opportunities for meaningful involvement with animal research, can be considered to contribute to an organisation's overall 'culture of care'.

A Culture of Care

A culture of care is a phrase used to emphasise the importance of a research culture that is focused on relationships, effective communication, and training and support. A good culture of care in animal research considers how to care for the humans as well as the animals within research facilities. It is aimed at providing better care for animals, but it is also about supporting and valuing interpersonal relationships and caring and respectful approaches to animals and to co-workers.

Building careful relationships is important for all involvement. We suggest foregrounding care is particularly vital in discussions of animal research as it raises sensitive and complex emotional issues. Extra care is needed to ensure that being involved in research is properly supported, and that people feel listened to and valued especially if conversations are uncomfortable, and able to step away at any point without affecting their other involvement work.

7.3. Enhancing involvement within institutions

There are further actions which funding bodies and other organisations can take to support and value involvement. These include both incremental actions, as well as more significant changes. We identify some of these below:

- **Supporting scientists to start involvement early.** Engagement around animal research currently tends to happen late in research, for example when sharing findings. This means that the experience of people affected by health conditions is not yet shaping research priorities or practices from the start. Funding involvement and supporting scientists to integrate involvement in scoping and developing research questions is important. If you are at an institution which internally reviews applications, you might ask internal grant panels to include people affected by health conditions to ensure involvement becomes common practice at all relevant project stages.
- **Training at every career stage.** Scientists often find themselves undertaking involvement and engagement without sufficient training. Institutions need to ensure people receive training for doing involvement and engagement work at relevant career stages and are given appropriate credit for undertaking this training. This might be delivered through training programmes, mentoring schemes, peer learning between experienced and newer staff, and working with external organisations who have in depth understanding of the involvement needs of their communities.
- **Sharing examples of good practice.** Organisations can play a valuable role in recognising and showcasing examples of involvement that have made a difference to an individual, a research team, or a project. This might be through developing and sharing case studies of good practice. You can find examples of these from organisations such as Cancer Research UK at the end of this chapter.

- **Providing competitive salaries for engagement and involvement practitioners.** Leading and running involvement and engagement requires particular professional skills and experiences. However, these roles are often precarious and underfunded. Offering appropriately funded salaries for long-term involvement and engagement roles is an important step towards recognising the skills that such a role requires.
- **Valuing qualitative evidence.** Institutions often seek to record the impact of involvement through quantitative measures or directly measurable changes. However, these do not adequately capture the impact of involvement, which are less tangible, such as those around relationships, empowerment, and trust. These can be built into grant and impact forms to allow applicants to include the quotes and reflections that capture and showcase the value of involvement work for everyone who has taken part.
- **Regular consultation and continuing conversations.** Doing involvement is always a learning process for individuals and institutions. Some things will go well and some things will not; both are part of learning and development. Institutional commitments to consult and reflect at regular intervals with scientists, people affected by health conditions, and engagement and involvement professionals can provide opportunities to learn from these and provide feedback to everyone involved. This is particularly important around animal research where continuing conversations need sensitivity to build mutual understanding.

7.4 References and further resources on involvement and research cultures

- Gorman, R. and Davies, G. (2020) When ‘cultures of care’ meet: Entanglements and accountabilities at the intersection of animal research and patient involvement in the UK, *Social and Cultural Geography* <https://doi.org/10.1080/14649365.2020.1814850>.
This academic article reviews the growing emphasis on a culture of care in clinical and animal research
- Munro, J (2020). We are missing the potential of patient feedback. Available at: <https://tinyurl.com/29tknnnu>
The Chief Executive of Care Opinion explains in [this short blog](#) how patient feedback is not currently being recognised as much as it could be in policy and practice. This blog forms part of the NIHR’s series of reviews on improving care through listening to patient feedback.
- Staley, K. & Barron, D. (2019) ‘Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation?’ Available at: <https://tinyurl.com/amcyj7cy>
In this academic article, Staley and Barron conceptualise involvement outcomes and impacts as ‘conversations that support two-way learning’. They discuss how having conversations and dialogue about learning can be useful for understanding impact, rather than a prescriptive method. These need to be tailored to the needs of the individuals involved, and the context. They suggest that the outcomes of involvement are subjective and unpredictable, and therefore what is learnt through doing involvement is as valid as the tangible difference that involvement might make.

8

CONCLUSIONS



8. CONCLUSIONS

Involvement and engagement are growing across all parts of research. Whether animal research is a stand-alone topic for discussion, or whether it is part of a wider research remit, it is important to be able to have the space to talk about it with other people and stakeholders. Through this report we have sought to identify some of the points where support might be useful, what sources and resources might help, and some questions you may wish to consider.

We have brought together some of the ways that involvement and engagement might enable people to have more open and transparent conversations around animal research. We have included questions, suggestions, and reflections throughout each chapter, highlighting the need for careful planning and relationship building. Involvement and animal research still face many challenges. Some of these are consistent across all involvement, such as the complex vocabularies of science, or an uncertainty about what difference involvement might make. Some are intensified around animal research when laboratory studies are further away from clinical outcomes and there are additional emotional and ethical dimensions to the use of animals in research.

With conversations about involvement only just developing in the context of animal research, now is a good time to think about how conversations might be better supported individually, collectively, and institutionally. Better support might be through extending cultures of care to those involved in research, through making incremental changes to existing practices, as well as embedding involvement more centrally within research cultures and institutional responsibilities. All encounters and actions are important, and we warmly welcome anyone reading and acting on this report to share their experiences and continue to build this conversation.





Funding by



Contact us

Prof Gail Davies

G.F.Davies@exeter.ac.uk

AnNex, c/o Gail Davies,
University of Exeter Amory Building,
Rennes Drive, Exeter Ex4 4RJ

+44 (0) 1392 723346