

# National Core Studies Immunity

## Patient and public involvement in COVID-19 research: bridging the gap between theory and practice

An exploration of best practice in patient  
and public involvement within the National  
Core Studies Immunity Programme



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## Introduction

Involving patients and members of the public in scientific research is not a new concept. Many researchers now consider this kind of involvement an integral part of their practice, and find increasingly innovative ways of ensuring that the views and feedback of public contributors shape their work. However, this is not true across the board and much research is still undertaken with little or no input from the people who may stand to benefit most from the work being done.

The idea for this report arose from discussions at a series of meetings between researchers working on various aspects of COVID-19 and a group of patients and members of the public. The researchers were all supported by the National Core Studies Immunity Programme, and had been invited to present their findings to a panel of members of the public with a range of backgrounds and experiences, to hear their views, questions and ideas. The panel were struck by the ways that some of these research teams had gone about involving patients or members of the public in their research, and the impact this involvement had in turn on the research.

The aim of this report is to share some of these examples from the perspective of those involved, with a view to improving understanding of how members of the public can be involved in scientific research in a way that is practical, effective, and reaps greatest reward for both researchers and public contributors.

Ultimately, we want to inspire more researchers to involve patients and the public in their work, and to provide those already doing so with a resource to demonstrate its wide-ranging positive impact to their colleagues, funders and to those whose decisions have a bearing on the UK's research landscape.



## What is the National Core Studies Immunity Programme?

At the start of the COVID-19 pandemic, UK funders of research and development, together with relevant experts, identified a number of areas where additional resource was needed to respond to urgent unanswered questions about COVID-19. As a result, the Government Office for Science established the National Core Studies (NCS) programme in the summer of 2020, to ensure that critical questions about the virus – and ways to combat it – could be answered quickly and effectively.

Six National Core Studies were set up, including the Immunity programme led by Paul Moss, Professor of Haematology at the University

of Birmingham. This study was funded by UK Research and Innovation and aimed to deepen our understanding of immunity against COVID-19, including how to predict individual risk, how to protect against infection, how to use vaccines to our best advantage, and how to prepare for future pandemics.

The National Core Studies are a crucial part of the UK's ongoing pandemic response, helping to ensure that health data and research inform our country's responses to the pandemic, as well as accelerating progress to establish a world-leading health data and research infrastructure for the future.



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## About the Patient and Public Involvement Panel for National Core Studies Immunity

COVID-19 has impacted on our lives in ways that are complex and far-reaching, with consequences that are vastly different from one person to the next. It is therefore crucially important to ensure that the views, ideas and perspectives of patients and the public can influence and shape the research being conducted in this area.

Early in 2022, a panel of patients and members of the public was recruited to work alongside the research teams supported by National Core Studies Immunity. The panel's ten members have a wide range of experiences and backgrounds, including some who have

conditions that affect how their immune system functions, and therefore their ability to respond to the COVID-19 vaccines.

The panel's role is to discuss the work being undertaken with the relevant research teams, and to offer insights and feedback on aspects of these projects, as well as their own personal perspectives of living with a variety of health conditions, where this is relevant to the research being conducted.

Ultimately, the purpose of the group is to ensure that COVID-19 research can most effectively meet the needs of the widest possible range of people.

Several members of the panel were involved in planning and shaping this report, and their comments and ideas are reflected throughout. They are:



### MO HAFEEZ

I am a carer for my disabled son, and also live with multiple long-term health conditions. I offer my experiences to many local communities, NHS services, Universities and PPI panels. I am practised at

analysing research documents and data as well as consulting on projects that work with young people with complex needs. I share knowledge and compassion on projects and ask questions that can make research better, and save lives.



### TONY KELLY

I worked for 30 years as an Equality & Diversity Manager and have a Socio-Legal Studies Masters Degree from the University of Birmingham. I was a Diabetes UK Community Champion

for nearly eight years, and am now a Diabetes Strategic Patient Partner at NHS Birmingham & Solihull Integrated Care System, as well as a Patient and Public Involvement representative at three universities. My diabetes has been controlled by physical activity and diet since diagnosis 18 years ago.

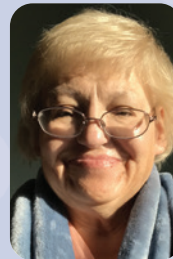


### LYNN LAIDLAW

I am passionate about involving patients in research, not just as participants but in governance and decision-making processes to shape health research from the outset through

involvement and co-production. I have extensive experience working with multiple organisations

and research teams across the UK, including National Core Studies Immunity, as a person with lived experience of health conditions, a patient contributor in research and as a patient researcher myself.



### DEB SMITH

I live with multiple long term health conditions, as well as supporting others who have health and social care needs. I have used health and social care services a lot and for the

last eleven years I have worked as someone with lived experience to improve these services and research in these fields. My work covers the UK and is extensive.



### VIVIENNE WILKES

I am from East Yorkshire and I've been a member of various PPI panels for several years in my local community and on a national level. I have been on panels looking

at equality and diversity, internal communications, and research. I have a particular interest in the disability sector both on a personal level and for the wider community with a particular interest in the blind and visually impaired communities. I have a true passion for the role of PPI and hope that I will continue to play a key role in PPI projects for many more years.

# What does it mean to involve members of the public in research?

One thing that was clear from the earliest stages of planning this report was the need to be clear about what we mean by *involvement* of patients and members of the public in research, and what this involvement looks like in practical terms when it is done well.

At the simplest level, to be involved in a research study in this context means your ideas, views and perspectives are sought on a variety of elements of a project, and acted upon in such a way that they impact how the research is done. These elements might include the project design, grant application (or application for ethics approval), approaches to recruitment and retention of participants, practical considerations and how the research results are communicated, but there is no limit to the aspects of a project that may be influenced by involving patients and the public.

It is possible for someone to be both a public contributor and a participant in the same research project. In fact, there is an increasing trend towards expanding the role of the research participant, where appropriate, into something beyond the traditional (and generally more passive) role of participant.

Where those involved have one or more medical conditions relevant to the research, they may be invited to share their experience of living with the illness, or provide specific advice or perspectives that only someone with the illness is in a position to give.

As such, being involved in research is not the same as participating in research, where someone agrees to take an experimental

medicine, provide samples, answer questionnaires, or otherwise contribute data, but has no influence over how the research is designed or managed.

It's important to stress that involvement may look very different from one project to the next, and that the degree of involvement may also vary from project to project. This is generally not a problem as long as the scope is clearly clarified at the outset, in terms of the responsibilities and influence the public contributors will have. Being open and transparent about this will allow people to decide whether they would like to become involved under those terms.

"It's far better to start small and incorporate a modest element of involvement in a project but do it really well, than to attempt something much larger scale that you simply don't have time for, or not do it at all," says Lynn. "Involving public contributors in qualitative research is going to be different from involving people in data science, for example, but the basic principles underpinning it are the same. This isn't about how-to checklists, this is about how to think mindfully about the values behind what you're doing."

"Patients and the public should be involved in projects at the very moment a researcher thinks about applying for funding for a grant," says Deb. "They should be seen as equals and colleagues, and everything possible should be done to facilitate their presence at meetings whether online or in person."

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## WHY INVOLVE PATIENTS AND THE PUBLIC?

The benefits of involving members of the public in research are numerous and wide-ranging, and it's important to establish and articulate early on what both sides are aiming to get out of the exercise.

"Involving patients and the public enriches research in a way that can't be achieved via any other means," says Deb. "It is so important to

have clinicians and researchers and members of the public working together – all of them bring something different that has value and a perspective that wouldn't be there otherwise. The result is better research that leads to better treatment and care for all who need it."

Mo adds: "When people come together from different perspectives and really work to understand each other's point of view, work a problem from different angles and

take decisions together, this can lead to huge benefits for both researchers and those who stand to benefit from that research.”

The benefits of involvement may be very concrete and practical, such as saving time or money, or they may be more subtle. The examples in the next section are intended to demonstrate some of the different forms these benefits can take, and how they outweigh the time and effort required to facilitate this involvement.

“As individuals, we have a lot of expertise about our own illnesses, and it’s important that researchers should have access to that perspective,” says Mo. “The best involvement asks really far-reaching questions – is there a different way to approach the research, has an important question been missed?”

Keeping an open mind is key to getting the most out of people’s feedback. Researchers often comment that the most important things

they learn from a group of public contributors are entirely unexpected. It’s also important to bear in mind that not everyone will always be in agreement, and that some feedback may be uncomfortable to hear.

“It’s about embracing what Sarah Knowles<sup>1</sup> and others have called ‘productive tensions;’” says Lynn. “We’re sometimes going to disagree, but that’s fine. Some researchers spend almost all their time in a lab or working with data, but when they speak to people who are affected by the illness they’re studying, they often find it adds a whole other dimension that can transform their work for the better.

“One of the surest ways to avoid a tokenistic approach to involvement is to be clear about why you’re doing it. For example, it’s really important to make sure you involve the right people. Will your particular project benefit from involving members of the general public, or do you need to hear from people with lived experience of a specific condition?”



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### THE IMPORTANCE OF BEING INCLUSIVE

One important aspect of involvement that is still too often overlooked is equity, equality, diversity and inclusion. There has historically been – and continues to be – a significant imbalance in the ethnicity and background of those who take part in scientific research (as participants, rather than public contributors), with the consequence that research is often skewed to cater to the needs of only a portion of society. This is likely in part due to a lack of trust in research and researchers among certain communities. One way to address this

imbalance is to proactively involve (as public contributors or ‘lay advisors’) people from groups less likely to engage with research, to seek their perspectives and views and act on their feedback.

“This issue remains of paramount importance in terms of positive action and changing the narrative,” says Tony. “The lack of representation from people who are Black Caribbean, Black African, Asian and White working class in particular cannot be understated. These groups are already

<sup>1</sup>More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production, Sarah Knowles et al, BMC, May 2021

marginalised and historically neglected, and I find myself pointing out to research teams again and again that they have not given enough thought to people with these backgrounds. That might be at the level of study design, recruitment of participants, the metrics set or the approach to communicating their results. If people with a broader range of backgrounds were routinely involved in research, there would be far fewer of these oversights.”

The task of ensuring fair and equitable access to opportunities to become involved in research is a complex one. Considerable thought, planning and proactive action is needed to promote and encourage participation from the widest possible range of backgrounds. In a world where researchers are often stretched for time and resource, the expertise of people from the most underrepresented groups is vital to solving this problem.

“People don’t necessarily fit into neat categories,” says Mo. “They may have a whole range of conditions that impact on their

everyday life, and these conditions might be complex or undiagnosed. They might be caring for a loved one, or in the position of being a carer and a patient at the same time. Researchers need to talk regularly to people in these situations to remind themselves of these complexities.

“As a patient, being involved in research gives you a platform to present yourself and to ask questions that are important to you. You’re representing yourself, and those you care for, but also anyone whose situation is similar to yours. This is particularly important for people from minority ethnic backgrounds – we can take what we’ve learned through being involved and share it with our communities, as a trusted source.”

Deb adds: “We need as wide a range of people as possible, and for people to know how to get involved. It’s the same problem that’s always existed: until people get involved, they don’t know about it. As soon as they do get involved, they learn about all sorts of different opportunities.”

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## CHALLENGES AND BARRIERS TO INVOLVEMENT

There are many valuable and effective resources available for researchers looking to involve public contributors (see links to some of these at the end of this section). However, these are not uniformly applied or integrated into research processes, and their discovery and uptake often relies on individual researchers taking an interest and happening to chance upon them.

“This is a false economy,” says Deb. “Researchers end up making the same old

mistakes over and over, instead of learning from the experiences of those who have done it before them. And we must remember this is often public money being spent. Training and awareness are so important.”

The embedding of high-quality involvement as an integral part of research practice requires dedicated policies, training, resources, support, and a solid infrastructure. “Once the necessary policy is in place, then the quality of the involvement being done improves,” says Vivienne. “The two things go hand in hand. There needs to be adequate training and structure. I’ve been involved in research before where I didn’t feel it was done professionally or well, and it leaves you in a vulnerable position and not wanting to do it again. But when it’s done well, when it’s organised and professional, when the boundaries are clear, you feel protected. This is so important.”

“So much value can be added to the planning, refining and sharing of research by involving patients and members of the public, and many researchers are becoming more vocal about the need to make this an integral part of research practice. When done well, it can be truly transformational.

**PAUL MOSS, Professor of Haematology at the University of Birmingham and Principal Investigator for National Core Studies Immunity**



Researchers who have already seen the positive impact of involvement and have integrated it into their practice are ideally placed to dispel some of the myths that discourage others, for example the idea that involvement is time-consuming, onerous and costly. There is an important role for these researchers in terms of championing and normalising involvement.

“When researchers make an effort to use simple language and break down complex information into a digestible format, and then listen carefully to how people respond to that information, they are drawing on a pool of lived experience that can throw a whole new light on their work,” says Mo.

And just as important as awareness among researchers is awareness among members of the public. Comparatively few people know that it’s possible to get involved in research, or how to go about this. “We need to encourage more people to get involved in research,” says Mo. “Everything else we do should contribute

“Researchers sometimes assume you need a group of 30 contributors, but the contribution of a panel of three can be just as valuable. It’s about doing it meaningfully and getting the best out of the people you have.

**VIVIENNE WILKES**

to that aim. People who have had difficult experiences with their health, or caring for loved ones, are often going through their own internal battles, and it can be very difficult to draw on and share this experience. But it is vital that these kinds of experiences shape, inform and improve research, and being involved in this process can be an extremely rewarding one, even if that reward sometimes comes later on in the process.”

Vivienne adds: “I’ve spoken to friends about becoming involved in research, and they often assume we’re just wheeled out by the researchers as a box-ticking exercise, that we’re not given any respect. We need to break this taboo. A lot of people don’t get involved because they fear they’ll be spoken down to.”

## Further resources

*NIHR Training and resources for public involvement in research*

*The impact of patient and public involvement in the UK Coronavirus Immunology Consortium*

*More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production, Sarah Knowles et al, BMC, May 2021*

*Who should I involve in my research and why? Patients, carers or the public? Kristina Staley et al, BMC, June 2021*

*‘Is it worth doing?’ Measuring the impact of patient and public involvement in research, Kristina Staley, BMC, July 2015*

*Getting It Wrong Most of The Time: Comparing Trialists’ Choice of Primary Outcome With What Patients And Health Professionals Want, Shaun Treweek et al, BMC, December 2021*

*Toward more mindful reporting of patient and public involvement in healthcare, Brett Scholz et al, BMC, September 2021*

## Examples of patient and public involvement

The following are examples of how research teams supported by National Core Studies Immunity have involved patients and members of the public in their work. This is not a comprehensive list, nor is it intended as a prescriptive lesson in how to involve people in research. Rather, these case studies are designed to give some insight into the different possible approaches to involving people in research in a way that is effective and meaningful, and allows for a positive experience for all those involved.

### A NOTE ON TERMINOLOGY

A wide range of terms and phrases may be used to describe the involvement of patients and members of the public in research, and to refer to the individuals involved. Some examples include: public contributors, patient and public involvement representatives, experts by experience, lay advisors. Ideally, terminology should be agreed upon with those being involved at the start of a project. The examples featured here may use different terms to describe their activity and those involved.

## EVITE IMMUNITY

The EVITE Immunity study, led by Helen Snooks, Professor of Health Services Research at Swansea University, is looking at the impact in Wales of the UK government's shielding policy for clinically vulnerable people during the pandemic, with a particular focus on health outcomes, immunity and cost.

"We knew it would be vitally important to involve people affected by the shielding policy from the very start of the process, and maintain that involvement throughout," says Helen. "So people who were advised to shield helped us design the study, and then were involved in every aspect thereafter."

Bridie Evans, Research Officer at Swansea University, leads the Patient and Public Involvement side of the study. "It made such a difference to have people who had been identified for shielding around the table at the very start when we were planning the study and applying for the funding," says Bridie. "They confirmed the importance of our research and brought a unique and invaluable perspective to the study design. For example, they pointed out the importance of understanding the different experiences of people according to health, economic circumstances, ethnic background and where they lived. They helped us write the application, and two were named



*We knew it would be vitally important to involve people affected by the shielding policy from the very start.*

**HELEN SNOOKS**

as co-applicants. They were as much a part of the team as anyone else. Two researchers were also affected by the shielding policy, which brought even more perspectives to our discussions."

Once the study's funding was secured, the public contributors became part of the Research Management Group which has coordinated and delivered the study. As well as being involved in all strategic decisions and ongoing management, they have a variety of roles, including as part of the team analysing interviews, such as those with the decision makers who designed the shielding policy.

They have also helped the researchers to understand how the shielding intervention changed over time, and highlighted the differences between 'shielding' and 'being shielded'. They co-author all research outputs including journal papers, conference presentations and reports, and will be involved in finalising analyses, synthesising results and writing up. They will also have the opportunity to co-present the study's findings to different audiences.

As well as involving public contributors through the Research Management Group, the study team also convened a Patient Advisory



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*I was suddenly faced with being labelled 'clinically vulnerable', and wondering what this virus might do to me if I caught it. It was a scary time.*

**LUCY DIXON**

Panel comprising eight people with experience of shielding. This group discussed and fed ideas and views back to the Research Management Group on topics such as the content of information sheets and questionnaires, the wording of interview questions and the use of patient stories to prompt reflections from health professionals.

The study is also advised by an independent Steering Committee that has two public contributors among its members, so that the public and patient perspective is fully heard and considered in discussions.

"One of the important things we gained from our colleagues affected by the shielding policy was insight into the wide range of their experiences", says Bridie. "If you haven't been identified for shielding, you simply can't know what it was like, or how it affected people in vastly different ways depending where they lived, the state of their health and their financial situation, the size of their family, and so on. And then the experience of any one person could also change over time. We hadn't appreciated just how complex the picture was until we started having these conversations."

All meetings have taken place via Zoom, and although some have missed face-to-face contact, collaborating online has made it easier for people to be involved regardless of geography, health or caring responsibilities that may otherwise have limited their ability to travel. And as the research team was also

meeting and working online, it meant that everyone's experience of meetings was equal.

Lucy Dixon became involved in the study after being advised to shield due to a rare disease called primary ciliary dyskinesia (PCD), which makes her particularly vulnerable to respiratory infections. "I really liked that it wasn't just about being a participant," says Lucy. "I had been involved in research in the past and it had sometimes felt quite tokenistic, but this felt like a role that really allowed me to be purposefully integrated into the project."

Lucy was invited to join the Research Management Group, and has been involved at all stages of the research, from planning to data analysis and dissemination.

"When the pandemic hit, I went from thinking of myself as a fairly healthy 29-year-old with a busy social life, to not seeing another soul for two months besides my parents, who I would wave at through a window. I was suddenly faced with being labelled 'clinically vulnerable', and wondering what this virus might do to me if I caught it. It was a scary time.

"As soon as I joined EVITE Immunity's Research Management Group, I felt like an equal partner in the process. I know my experience is a valued and valuable element of the team's skills and knowledge, which will help us do the best research we can on this important subject. It's been an incredibly rewarding research project to be involved in."



*If you haven't been identified for shielding, you simply can't know what it was like.*

**BRIDIE EVANS**

## BE-DIRECT

Over the course of the pandemic, it has become clear that people from some ethnic minority groups are at greater risk from COVID-19 than people of White ethnicity. The aim of the BE-DIRECT study, led by Manish Pareek, Professor of Infectious Diseases at the University of Leicester, is to explore whether and how immune responses play a role in this disparity. BE-DIRECT is part of the wider UK-REACH study, which aims to gain a better understanding of COVID-19 outcomes in minority ethnic healthcare workers.

BE-DIRECT is advised by a Professional Experts Panel (PEP) of ten people who work in a variety of healthcare roles. A work package dedicated to involvement was built in to the project from the start, and one of the researchers, Mayuri Gogoi, has been helping with the coordination and facilitation of the PEP.

"The PEP reviews all project materials such as surveys and upcoming papers, discusses upcoming research priorities, makes sure language used is appropriate, and advises on the dissemination of our findings," says Mayuri. "They have been instrumental in a number of areas of the study, and some have co-authored papers with the research team. Their input is integral to the success of the study.

"For example, BE-DIRECT relies on data gathered on the ground, so the surveys have been crucial to its success. The PEP reviewed the questions, making sure these were well-matched to the various target groups, and used language that would be easily understood."

Manish adds: "It was so important to us to involve people affected by the issues we were studying, and to do so in a way that was meaningful and empowering. We were

very conscious that there are many reasons why people from ethnic minorities were being disproportionately affected by the pandemic, and that this was a sensitive and emotive issue.

"We also knew we needed to hear from people in a wide range of different healthcare roles. Only they could give us the feedback we needed on how our materials and findings would be received by their colleagues, on the topics that really mattered to them, and on the very practical issues they face day to day. They have been an absolute pleasure to work with."

Advanced Nurse Practitioner, Susie Lagrata, is Co-Chair of the PEP. "UK-REACH approached me via the Filipino Nurses' Association, and asked me to be part of the PEP," says Susie. "I'm very interested in research but was still hesitant at first, and later when I was asked to Co-Chair the group, I took some persuading as it's not really in my nature to put myself forward for things like that. But the study team were very encouraging and I never felt that I didn't belong, or that my opinion was any less valuable than anyone else's.

"As things went on, I became more confident and felt less intimidated. Now it's like speaking



*It was so important to us to involve people affected by the issues we were studying, and to do so in a way that was meaningful and empowering.*

**MANISH PAREEK**



*The study team were very encouraging and I never felt that I didn't belong, or that my opinion was any less valuable than anyone else's.*

**SUSIE LAGRATA**



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to a group of friends. I've even been able to inspire other Filipino nurses to be involved. Seeing someone that looks and speaks like them, and has the same experiences on the ground has helped with this. I could help them understand that it wasn't simply a tick box exercise."

One challenge has been ensuring a good cross section of roles in the panel membership, and this is something the study team continues to work on. "We needed representatives from every area of healthcare, including nurses, porters, admin staff, cleaning staff," says Susie. "We still have work to do to empower our colleagues in certain roles, but we are making a start. At every meeting we discuss possible ways of making it more inclusive, and we've been careful to foster a culture where people can be open, to establish a safe space where all lived experience is valid and valued. For example, we make it clear that anything said in the meeting is confidential, and the meetings are never recorded."

Time is another challenge, given the pressures on healthcare staff. "Finding time can be a challenge as we are all very busy,"



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**SUSIE LAGRATA**

explains Susie. "Often I find myself giving up a few hours of my evening. Maybe in future, this kind of involvement could be included in someone's job plan. This makes sense, as ultimately, it will have benefits for healthcare professionals more broadly."

But Susie has no doubts as to the positives of being involved. "It was an amazing opportunity to be able to co-author some of the papers that came out of the study. This was great for my own professional development. Another more unexpected benefit is that I've been able to make connections with people in roles and departments that I wouldn't normally have contact with, and that has had benefits in my day-to-day work. We now know each other well and can help each other out in other ways."

And the group continues to have an impact beyond BE-DIRECT too. Mayuri explains: "The PEP is now providing input into additional areas of work, such as the REACH-OUT study on Long Covid among healthcare workers, which is funded by the NHS Race and Health Observatory. Overall, the group's influence will be far-reaching."

## THE VACCINE BREAKTHROUGH PROJECT

When someone who is vaccinated against COVID-19 becomes infected with the virus, this is described as a 'breakthrough infection'. A team led by Aziz Sheikh, Professor of Primary Care Research at Edinburgh University, is investigating these infections to understand who is most at risk.

Patients and members of the public have been involved at various stages of the project, and have helped to identify areas where public involvement would be beneficial. These include how data on the shielding population is captured, how risk is represented and analysed, and how health outcomes are defined. "We also stressed that it would be important to accompany the data with patient stories," says Lynn Laidlaw, PPI Co-Lead on the project. "Some people are still shielding, particularly those now eligible for monoclonal antibody or antiviral treatments. They still don't know what their own individual risk is of becoming severely ill with COVID-19, and it's vitally important their voices are heard."



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**LYNN LAIDLAW**

The project has a dedicated involvement strategy with an accompanying budget and defined, measurable goals. There is also a dedicated Patient and Public Involvement

(PPI) Team, which includes two members of the public as PPI Co-Leads. A PPI Coordinator oversees all the activity and manages the logistics.

"It makes such a difference to have a member of the team taking responsibility for coordinating all the involvement," says Lynn. "It demonstrates the team's commitment to involving patients and the public, and is an acknowledgement of the value they place on this. In a practical sense, it also helps to make processes and logistics seamless. Things like being given a choice of how we are paid for our time actually make a big difference to our experience of being involved."

The study's researchers present their results to the PPI Team prior to publication, inviting views on the interpretation of the data and how it can best be presented to a non-scientific audience. "It was very clear to those of us who had shielded that there needed to be a great deal of consideration as to how these results were communicated to people in our situation," says Lynn. "It's one thing to share the information with policy makers so they can alter vaccination schedules, but how is the evidence then passed on to patients and their clinical teams?"

To this end, the team wrote research summaries in plain English, and produced short soundbites that could be shared on social media. "We wanted to tell people about this research in a way that was easy to engage with, and explain in simple terms how the findings would shape public policy," says Deb Smith, another of the project's PPI Co-Leads. "It takes a lot of emotional investment to offer a personal perspective to be shared with the public, and it can sometimes be a challenge to reconcile your own experience with the



*It makes such a difference to have a member of the team taking responsibility for coordinating all the involvement.*

**LYNN LAIDLAW**



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project's public messaging. We worked hard to get this right, and it has definitely been a learning experience on both sides.

"Part of the challenge is that it's an incredibly fast-moving project, so much of the processing of the thoughts and emotions that arise from it takes place outside of the hours you actually spend contributing. This is probably the case for any project with lay advisors."

Lana Woolford, the project's PPI Coordinator, comments: "Lynn and Deb have been a fantastic asset to this project, not only because of their lived experience but because they sit on the overarching National Core Studies Immunity PPI panel too, so they have a much better overview of all the studies supported by the programme.

"They were involved in co-producing the project's involvement strategy and setting our focus. For example, they helped us decide to prioritise communication with people who will be particularly impacted by any policy decisions that may arise from the project.

"We had some great conversations about things like how different illnesses might

interact in terms of vaccine breakthrough, and about body mass index. They have also been involved in setting priorities to apply for some further funding, and commenting on the application for this."

The project's next priority is to study vaccine breakthrough during the vaccine booster campaigns. The PPI Co-Leads have identified several research priorities to be taken forward by the researchers. "We had a discussion about how to make sure the research findings are communicated to the people affected and the clinicians caring for them, to enable them to make informed decisions," says Lynn. "This is a step that's still too often forgotten, but it's so important that results filter out beyond academia, and reach those who are most at risk."

In light of these conversations, the research team is now planning a review of all research from the broader EAVE II project, in order to draw together all the evidence relevant to people who may be especially vulnerable. This review will be studied by the project's PPI Team before publication so they can identify any gaps, and they will advise on how it can be effectively disseminated to patients and their health teams.



*We wanted to tell people about this research in a way that was easy to engage with, and explain in simple terms how the findings would shape public policy.*

**DEB SMITH**

## VIBRANT

The VIBRANT study, led by Alex Richter, Professor of Clinical Immunology at the University of Birmingham, and Paul Klenerman, Sidney Truelove Professor of Gastroenterology at the University of Oxford, is investigating why some people experience breakthrough infections after COVID-19 vaccination, become infected more than once, or fail to mount an immune response following vaccination or infection. VIBRANT is part of SIREN, a UK-wide prospective cohort study established early on in the pandemic by the UK Health Security Agency. The SIREN study monitors COVID-19 infections and the immune response in over 44,000 healthcare workers, making it the largest study of its kind anywhere in the world.

At its core, the SIREN study is a collaboration between participants and researchers. To ensure participant feedback is heard, respected and influences research, SIREN established a Participant Involvement Panel (PIP). The PIP is made up of ten SIREN participants and meets on a six-weekly basis. The SIREN research team, along with partner studies such as VIBRANT, are able to approach the PIP to



*The panel's input probably sped up the whole process of getting ethics approval by about a month. Involving public contributors doesn't just make a study better, it makes it quicker.*

ALEX RICHTER



*We really feel like part of the team. And even though it's a significant investment of time, it isn't ever a chore. It's enjoyable.*

JIMMY PAGE

request feedback and advice on a wide range of topics.

"We got some fabulous advice right at the start about how to engage with healthcare professionals," says Alex. "The panel's input probably sped up the whole process of getting ethics approval by about a month. Involving public contributors doesn't just make a study better, it makes it quicker.

"The panel gave me huge confidence in what we were doing. When you put in applications like these, you base them on what you think is important as a scientist, but you are just one person and it's a big responsibility to make that judgment by yourself. The panel confirmed in my mind that this was something really worth investigating, worth pursuing and spending valuable time on."

The SIREN research team were eager to ensure the panel included a diverse mix of individuals representing a broad range of professions, geographic regions and demographic groups such as ethnicity, age and gender.

"There is a huge variety of people in the group", says Jimmy Page, a member of the panel. "I'm from a data analytics background, but we have nurses, consultants, people from different parts of the UK. It's a really diverse mix.



**VIBRANT**

**V**ACCINE **I**MMUNITY, **B**REAKTHROUGH &  
**R**EINFECTION – **A**NTIBODIES & **T**-CELLS



“Both the panel and the research team are very friendly and supportive. Everyone is on an equal playing field – the researchers will come to us with an idea and want our view on it before they invest time and money in it. We really feel like part of the team. And even though it’s a significant investment of time, it isn’t ever a chore. It’s enjoyable.”

The scale of the SIREN study is one of its key strengths but also presents a challenge – 135 NHS hospital sites are involved, as well as all four UK public health agencies. The PIP has been a valuable way of gathering views from across the network.

“We are viewed as the local experts, with in-depth knowledge about our respective NHS Trusts,” says Jimmy. “We can pick up practical points that help embed the research project in each area. I can go away and talk to my team about the research, get views from them and then feed them back. In a way, we’re champions for the study in our area, telling people about it and getting them interested. I’ve spoken to colleagues who are now interested in becoming involved themselves.”

The panel also helps researchers take a step back from materials they were preparing for participants, and consider how these would be received. “We can look at information intended for healthcare workers who might not have a research background, and advise on the most appropriate language,” says Jimmy.

Alex adds: “The questionnaire for participants was so much better and clearer because of the feedback we got, and the Frequently Asked Questions for the website were much improved too. This has been so helpful, and meant our communications were quicker and more effective.”

The VIBRANT study team enlisted the help and expertise of the British Society for Immunology to coordinate the panel and advise on how to make it as effective and inclusive as possible.

“I like the fact that there are a range of opportunities to contribute in different ways, depending on your preferences and skills,” says Kim Tolley, a Clinical Nurse who is also a member of the panel. “We are invited to co-chair meetings if that’s something that appeals to us. I’ve been interviewed for a public-facing video about the study. The research team appreciates that we’re all unique individuals who want to get involved in different ways, and have a range of skills to offer.”

“We are empowered to ask questions, no matter how obvious or basic they seem to us. We feel really listened to and valued, and that’s really important. We are partners in this.”



*My children may see more pandemics in future and my contribution will have played a part in protecting them.*

**KIM TOLLEY**

“One thing that’s really important is that the research team comes back to thank us for our advice, and explains what they’ve done with our input, including the specific changes they’ve made. It shows that you’ve been listened to and valued for your contribution.”

“For me, the personal impact of being involved is substantial. My children may see more pandemics in future and my contribution will have played a part in protecting them.”

## NATIONAL CORE STUDIES IMMUNITY PATIENT AND PUBLIC INVOLVEMENT PANEL



*The researchers always appreciate this opportunity to see their work in a new light and address issues they may not previously have thought of.*

**ERIKA AQUINO**

In addition to the involvement of patients and the public in the individual research projects supported by National Core Studies Immunity, an additional panel of ten public contributors has a more overarching role advising and feeding back on the work taking place. This panel is co-ordinated by the British Society for Immunology (BSI).

The members of this panel have a wide range of backgrounds and knowledge, including some with experiences of particular relevance to the research programme, such as shielding or having a condition that affects the immune system. National Core Studies Immunity teams regularly present their work to this panel, sometimes in its early stages or before results are published. Thoughts, reflections and ideas are then sought from the panel members, and the discussions that ensue are often lively and thought-provoking.

“All views are respected and the environment is always inclusive of all perspectives, which ensures the panel members have a powerful voice at the table,” says Erika Aquino, Public Engagement Manager at the BSI and lead for PPI within National Core Studies Immunity. “Individuals on the panel raise interesting and sometimes challenging questions that lead to important discussions. The researchers always appreciate this opportunity to see their work in a new light and address issues they may not previously have thought of.”

Topics covered at these meetings have included the challenge of recruiting from different patient and ethnic groups, the importance of linking up with relevant patient charities, and the imperative to communicate findings in plain English and via the channels

that will be most effective in reaching communities. They have helped to draw attention to research questions that may have been neglected, or helped to shed light on the reasons for an imbalance in the diversity of participants in a project.

Not every study in the programme has involvement embedded in it, so for some research teams, this may be the only opportunity they have to hear the views of a group of patients and members of the public.

“We can act as a sense-check,” says Deb. “We have the advantage of being able to see across lots of studies that don’t necessarily have much contact with each other. We can help to cross-pollinate good ideas.”

Many of the panel’s members are active in communities of people from a particular background or with a specific condition, and can take news, findings and developments back to those networks, who then filter the information out further. They can also advise on how sensitive findings may be received by



*We have the advantage of being able to see across lots of studies that don't necessarily have much contact with each other. We can help to cross-pollinate good ideas.*

**DEB SMITH**



A National Core Studies Immunity PPI panel meeting on Zoom

particular groups, and pick up on language that's not appropriate, or that could be confusing for a non-scientist.

"Researchers can get into the habit of using terms such as *cohort*, *burden*, *morbidity*, which are quite dehumanising," says Lynn. "We can remind them of how people prefer to describe themselves, and advise on the language that will work best when it comes to communicating their findings to the public."

In addition to the meetings, research teams can draw on the panel's expertise on a particular topic, or run materials past them for feedback. "It helps that the Programme's leadership place enormous value on the panel," says Vivienne. "They remind teams that, though they are busy and under pressure, this is still an extremely important resource for them to draw upon."

Lynn adds: "The response to the COVID-19 pandemic was so fast paced and high pressured. Our meetings can be an opportunity to stop and think about things in a way that might not happen easily in the lab environment or when performing data analyses. We can pick up on things that the researchers may simply have been too busy to think about."

Crucial to the success of the panel has been the decision to allocate dedicated funds for it. "Building in financial support for PPI at the start of a project is essential to embedding it successfully," explains Erika. "By drawing on the BSI's specialist knowledge and professional management of the panel, the National Core Studies Immunity team were able to achieve a seamless and productive experience for both the researchers and the panel members."



*Our meetings can be an opportunity to stop and think about things in a way that might not happen easily in the lab environment or when performing data analyses*

**LYNN LAIDLAW**

## Looking to the future

The examples presented here are compelling proof that the involvement of patients and members of the public in scientific research can make that research more comprehensive and better tailored to those who stand to benefit most from it. It can help to ensure the right research questions are tackled in the right way. It can speed up processes and reduce costs. It can help research to filter out beyond academia to healthcare settings and patient groups, and be better understood by the general public. It can strengthen public trust in research and scientists. And all of this can be achieved even in a context as challenging and fast-paced as the research response to the COVID-19 pandemic.

This all bodes well for the future of involvement. We are confident that powerful, inspiring examples will continue to emerge, and

that the positive impact of involving patients and the public in research will become ever more apparent.

### A FLEXIBLE, SELF-REFLEXIVE APPROACH

The range of approaches reflected here, as well as the variety of methodologies, types of project and people involved, show just how limitless the possibilities for involvement are. There is no one-size-fits-all approach. And while this allows for a lot of flexibility, it can also be daunting for a researcher who may not be sure how best to involve people in a particular project. The key is to keep an open mind throughout the process.

"It is so important to really reflect about what you're doing, what's going well, what isn't, what you might do differently going forward with the public contributors involved," says Lynn. "This step is so often missed out, but this is what ensures you're not doing involvement because everyone's doing it, or because you need to do it to get funding, or to tick a box."

And just as one researcher's approach may change with practice, the role of research participants, public contributors and even researchers themselves will likely evolve over time. The pandemic saw a rapid change in certain research practices out of sheer necessity, and opened up possibilities for new ways of doing things. "We've already seen involvement and engagement move more towards co-production in some cases," says Deb. "The more involvement can grow and develop, the better."

"There is starting to be a shift in how researchers see the people who take part in their research," adds Lynn. "They are realising that there is potential to involve people much more fully, and that their research will be much stronger and more complete for it. I think we will begin to see much more overlap between the role of research participants and public contributors, which have up until now been quite separate."

It's about building trusting relationships and, crucially, in a research world that's really busy, making the time.

LYNN LAIDLAW



“We need to introduce the principle of involvement to researchers who've not done it before.”

VIVIENNE WILKES

### SPARKING CONVERSATIONS

One theme that ran through all the discussions that helped to shape this report is the importance of dialogue, and of presenting the perspectives of researchers and members of the public alongside each other, with equal value.

“When researchers and people who have been involved in research stand side by side and wave the same flag, say the same thing, standing together as a united voice, that has huge impact,” says Vivienne. “If we can increase the appetite for involvement on both sides – among researchers and members of the public – this could give the impetus needed to normalise it.”

Lynn adds: “It’s about building trusting relationships and, crucially, in a research world that’s really busy, making the time.”

The experiences of the teams featured here will equip them to involve people even more meaningfully in future, to find new reasons to involve them and new ways to do so. Our hope is that by sharing these examples widely, they will also inspire others to follow suit and take steps – perhaps their first – to discover what patients and members of the public can contribute to their research, and the many (sometimes surprising) ways in which their research will be better for it.

“We need to introduce the principle of involvement to researchers who've not done it before,” says Vivienne. “They need to hear that this is something their colleagues are doing more and more, that they place value on. Often the first step is to spark a conversation, to put the seed of an idea in someone’s mind. That’s when you start changing people’s behaviour.”

Mo adds: “We have some really, really good examples from the National Core Studies – this is the evidence. It shows that it’s working. We need to share examples of when this has really worked and had an impact, so that others will feel empowered to do it too.”

Researchers themselves can, of course, be powerful champions for involvement, spreading the word among colleagues and helping to embed good practice. But there is also an important role for funders, academic institutions and policy makers. “When there is a solid structure around involvement, when policy is embedded and there are proper guidelines, then the quality improves,” says Vivienne. “But until the people making decisions actively promote the importance and benefits of involvement, many still won’t take it seriously.”

We invite researchers to use this report to begin conversations about patient and public involvement with colleagues, funders, research institutions, charities, policy makers and members of the public. We encourage those who have not previously involved patients or the public in their work to reflect on where they might take a first step – no matter how small – towards doing so. And we urge people of all backgrounds and ethnicities, regardless of where you live or which communities you belong to, to consider becoming involved in research. You could help to ensure that science responds to the needs of every one of us.

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