Amplifying patient involvement in translational research

A report by the Charities Research Involvement Group, LifeArc and the Translating and Accelerating Research Network

tar network
TRANSLATING & ACCELERATING RESEARCH

Charities Research Involvement Group

LifeArc

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Introduction

This is a report of an event organised by the Charities Research Involvement Group (CRIG), LifeArc and the Translating and Accelerating Research Network (TAR) on 22nd May 2025. The event, entitled *Amplifying patient involvement in translational research*, was attended by people with lived experience, members of CRIG and TAR and their colleagues.

The event aimed to:

Explore

Explore the value and impact of patient and public involvement across various aspects of translational research – e.g. involvement in individual research studies, research programmes, at a strategic level and in funding decisions

Discuss

Discuss the challenges of involving people with lived experience in translational research

Identify

Identify practical strategies that could help CRIG and TAR members to advance PPI in their work

Collaborate

Collaboratively identify priority areas for action

A note about the language used in this report

In this report, we use the term *people with lived experience* to describe people who use (wish to use, or have used) health and/or social care services. This includes parents, carers and family members as well as people who directly use services. We do not mean all users of an organisation's services, as this may include, for example, health professionals. Some organisations prefer the terms 'patients', 'public', or 'people affected by...'

We use the term *involvement* to cover a range of activities, from consulting people with lived experience about their views or wishes, through to working in partnership with them to develop, carry out and/or disseminate the findings of research. When we talk about involvement, we mean the active involvement of people with lived experience, not their passive involvement as recipients of research. Involvement is often described as doing things *with* people, rather than *for* or *to* them. Some organisations use the term 'patient and public involvement', or PPI.

We talk about what translational research is later in this report.

About the organisations that put together the event

Charities Research Involvement Group

The Charities Research Involvement Group (CRIG) brings together UK based charities to share learning about the involvement of people with lived experience in research. It has around 70 members.

LifeArc

LifeArc aims to transform scientific discoveries into impact for patients with rare diseases and in global health. It focuses on translational research, including translational research advice and translational research funding.

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TRANSLATING & ACCELERATING RESEARCH

The Translating and Accelerating Research Network (TAR) is a consortium of 40 medical research charities. Run by Prostate Cancer Research, it aims to inform and accelerate best practice in translational research. Its goal is to ensure better patient outcomes for everyone.

Thanks to all of the speakers at the event:

Bhavna Tailor, Stargardt's Connected
Lorna Allen, Cystic Fibrosis Trust
Clare Farmer, Versus Arthritis
Lucy Davies, Lucida Medical
Emily Reuben, Duchenne UK

All of the speakers as well as the participants helped to shape this report. Thanks to them for their help. There is a list of participants at the end of this document.

Thanks to **Heart Research UK** for enabling Sally Spawforth to be part of the planning team for this event.

Thanks to LifeArc for providing funding to stage this event and write up this report and to Debbie Nichol for providing organisational support.

Thanks to **Prostate Cancer Research** for their continued funding of the TAR Network which was integral to the planning and delivery of this event.

What is translational research?

Translational research transforms scientific discoveries into new treatments and medical practices to improve people's health. Translational research occurs in both commercial (e.g. pharma companies) and academic (e.g., universities) settings. Often referred to as research that 'bridges the gap', it helps move discoveries 'from the bench to the bedside' and works towards ensuring they:

- **Are safe and effective**
- **Are cost effective and improve efficiency**
- **Work in real-world settings**
- **Deliver real benefits to patients and society**
- **Are possible to develop and use**

We asked participants at the event to comment on this proposed definition. Some of the themes that emerged from these comments included:

"The important thing about translational research is that there is an intent to exploit, commercialise or 'productise' an initial discovery – so that it can be developed or used"

"We need to include something in the definition about speed – research needs to be translated rapidly so that it can lead to better health outcomes for people. But we also need to recognise that research takes time"

"Translational research is the bit that happens between basic research and clinical research – it's about working out whether innovations have the potential to be applied in a real-life setting"

"Many people don't fully understand what translational research is – but this doesn't necessarily matter. The important thing is that people with lived experience are involved at all stages of the research process"

"Should translational research be re-named *transformational* research?"

What does involvement in translational research look like?

Speakers at our event shared some examples of how involvement is shaping translational research:

Stargardt's Connected

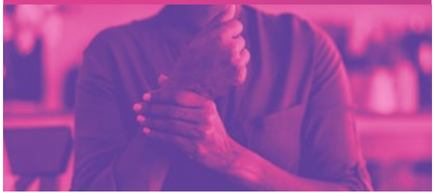
Stargardt's is an inherited progressive disease that causes vision loss in children and young adults. Bhavna Tailor founded the charity Stargardt's Connected after her son was diagnosed with the condition.

Cystic Fibrosis Trust

Cystic fibrosis (CF) is a rare inherited genetic condition causing systemic cellular malfunction, manifesting most commonly in breathing and digestive problems. There is currently no cure, but recent modulating treatments have dramatically improved quality of life for many people with CF.

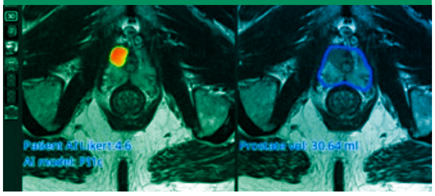
Versus Arthritis

There are over 10 million people living with arthritis in the UK. Versus Arthritis works to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes. Clare Farmer is a Research Programme Manager at Versus Arthritis.



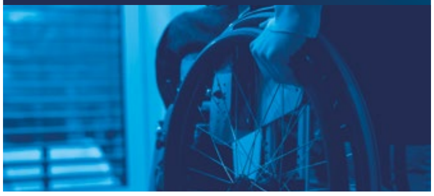
Lucida Medical

Lucida Medical develops software tools using AI and MRI, to support cancer screening, diagnosis and management. Lucy Davies is VP Clinical.



Duchenne Muscular Dystrophy

Duchenne muscular dystrophy (DMD) is a progressive disease which is usually diagnosed in boys between the ages of 3 and 6. Emily Reuben OBE is the co-founder and CEO of Duchenne UK. Her eldest son lives with DMD.



Stargardt's Connected

Stargardt's is an inherited progressive disease that causes vision loss in children and young adults. Bhavna Tailor founded the charity Stargardt's Connected after her son was diagnosed with the condition.

Why did Stargardt's Connected choose to get involved in translational research?

One of the things Bhavna was keen for the charity to do was to stimulate and fund research, as there was very little research taking place.

How are people affected by Stargardt's Connected involved in translational research?

The charity has worked hard to ensure people with lived experience of Stargardt's can be involved in research. They have:

- Organised the first international research network meeting about Stargardt's, which brought together companies, people affected by Stargardt's and researchers to identify research gaps and develop a proceedings paper for a scientific journal.
- Involved young people in research discussions
- Created a patient register spanning 56 countries to stimulate research and aid trial recruitment.
- Established regular meetings with pharmaceutical companies early in the treatment design process to incorporate patient perspectives
- Organised community zoom sessions on various topics, including clinical trial processes and upcoming gene therapies, to provide learning and engagement opportunities.

What are the challenges?

People affected by Stargardt's may not always appreciate the added value they offer to research, and they can lack confidence in advocating for research and for their involvement in it. Other challenges include the episodic nature of pharmaceutical company contact, accessibility issues, and the small size and funding limitations of rare disease communities.

What has the impact been so far?

People affected by Stargardt's have already helped to move research forward. Researchers have been inspired by their contact with people affected by the disease and say they want to collaborate more. The international conference provided insightful experiences for researchers and enabled them to hear directly from people affected by Stargardt's in a safe space.

The charity played a key role in supporting a pharmaceutical company in conversations with regulators to amend recruitment criteria for a clinical trial which enabled more people to take part.

Top tips for involvement in translational research

Tip 1: Recognise that people with lived experience may underestimate their value. Provide opportunities, encouragement, and safe spaces for involvement

Tip 2: Develop infrastructure, like patient registries or educational resources, to empower the community and support trial readiness

Tip 3: Proactively connect people with lived experience, researchers, and industry at the earliest stages of research to co-shape priorities and trial design.

Cystic Fibrosis Trust

Cystic fibrosis (CF) is a rare inherited genetic condition causing systemic cellular malfunction, manifesting most commonly in breathing and digestive problems. There is currently no cure, but recent modulating treatments have dramatically improved quality of life for many people with CF. Lorna Allen is the Involvement Manager at CF Trust. Her daughter lives with CF.

Why did the CF Trust choose to get involved in translational research?

People living with CF have to take a wide variety of medications. Numerous drugs that have been developed in isolation must be taken in combination, often compromising prescribed dosing protocols and therefore optimum efficacy. People with CF are not defined solely by their condition – they often lead busy lives alongside managing a heavy treatment burden, making it crucial for treatments to pragmatically integrate into their routines.

CF Trust wanted to ensure that people affected by CF informed the development of new treatments in order minimize negative impact on their lives, whilst making sure that the practical administration and tolerability of any new drugs supported adherence and therefore optimum efficacy. So they have been promoting their PPIE support service to commercial organisations to engage with people affected by CF earlier in the concept and design phase.

How are people affected by CF involved in translational research?

In collaboration with LifeArc and the Medicines Discovery Catapult, the CF Trust forms the CF AMR Syndicate. Collectively working on target product profiles (TPPs)[1], has defined ideal and minimum acceptable characteristics of treatments from the patient perspective. Two TPPs have been created in partnership with people affected by CF – providing 'blueprints' for new **antimicrobial antibiotic therapeutics**, and innovative diagnostics to detect, diagnose and **monitor lung infections**.

What are the challenges?

There was some initial challenges in educating the community about the purpose and application of a Target Product Profile to help them understand why their lived expertise was so valuable at this stage of product development. There are obviously also scientific and clinical limitations that may prevent some patient preferences being incorporated or adopted, but again, with thorough explanation these can be mitigated and actually lead to valuable consideration for adaptive or alternative options throughout the process.

What has the impact been so far?

The value and impact of the published Target Product Profiles is two-fold. First, their intended use to provide a framework for product development has proved beneficial. They are publicly available and have had a number of downloads from the website. Funding applicants have already made use of their content leading to successful funding outcomes.

Second, the novel approach to developing the target product profiles has been presented at several conferences, receiving a positive response from pharmaceutical companies who are familiar with TPPs but have not previously considered the benefits of initiating their development from the lived expertise of patients. The model used featured in the **Global Forum industry publication** and the collaborative approach of the CF AMR Syndicate to developing TPPs was recognised at the **OBN Awards 2024** providing further opportunities to amplify the voice and experiences of people living with CF.

Top tips for involvement in translational research

Tip 4: Consider developing tools such as Target Product Profiles (TPPs) to clearly articulate patient-defined preferences.

Tip 5: Engage commercial developers before research protocols are fixed to shape how products are developed.

Tip 6: Anchor involvement in an understanding of people's broader lives, not just their symptoms or biology.

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[1] | Target product profiles are documents that describe the desired characteristics of a product. They are often used in health research. They specify the intended use, target populations, and desired attributes of products, and can be used for medicines, vaccines, diagnostic tools, and medical equipment. They can support evidence generation for regulatory submissions and ensure products meet public health needs.

Versus Arthritis

There are over 10 million people living with arthritis in the UK. Versus Arthritis works to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes. Clare Farmer is a Research Programme Manager at Versus Arthritis.

Why has Versus Arthritis involved people with lived experience in translational research?

Versus Arthritis is committed to actively involving people with lived experience of arthritis in research. The charity supports a group of over 130 people with lived experience of arthritis who work in partnership with research staff to make decisions about the charity's research. They are called Research Partners and they are involved at every stage of the research process.

How are people with lived experience involved in translational research?

This year Versus Arthritis issued a translational research call, seeking high-quality proof of concept projects that aim to develop a commercially viable technology.

This technology should address a clear unmet clinical need for people with arthritis. The funding aims to advance technologies, making them more competitive for larger grants. Applicants are expected to show that they have involved people with lived experience in the development of their project, and plan to continue to involve them through the delivery of the project.

Research Partners have reviewed applications for this funding. In common with all other Versus Arthritis research funding calls, the panel meeting - where decisions are made about what research to fund - is co-chaired by a Research Partner.

When reviewing funding applications, Research Partners were asked to consider:

- Importance and potential impact
- Relevance and scope
- How people with lived experience of arthritis were involved in the development of the application, and how they will be involved if the application is funded
- The design of the research and the plans for delivery

What are the challenges?

A number of challenges have been identified to date. They include:

- The time and resources required to support meaningful involvement
- The nature of arthritis can impact on how people can be involved
- It can be hard to communicate effectively about the technical aspects of translational research
- Setting and managing expectations
- It takes time to develop, maintain and manage relationships with people
- Ensuring that the views of Research Partners broadly reflect the broader community of people affected by arthritis

The Versus Arthritis research team are already working to help researchers to use plain language and to understand the expectations around patient involvement at the translational research stage.

What has the impact been so far?

The funding call is not yet complete, but the charity is already seeing the impact of involvement. Research Partners have been able to provide useful comments about the relevance, acceptability and quality of funding applications. Research partners have increased their skills and knowledge and built their confidence to be more involved in this type of research. At the end of the funding call an evaluation is planned, so it's likely that more impacts will become clear.

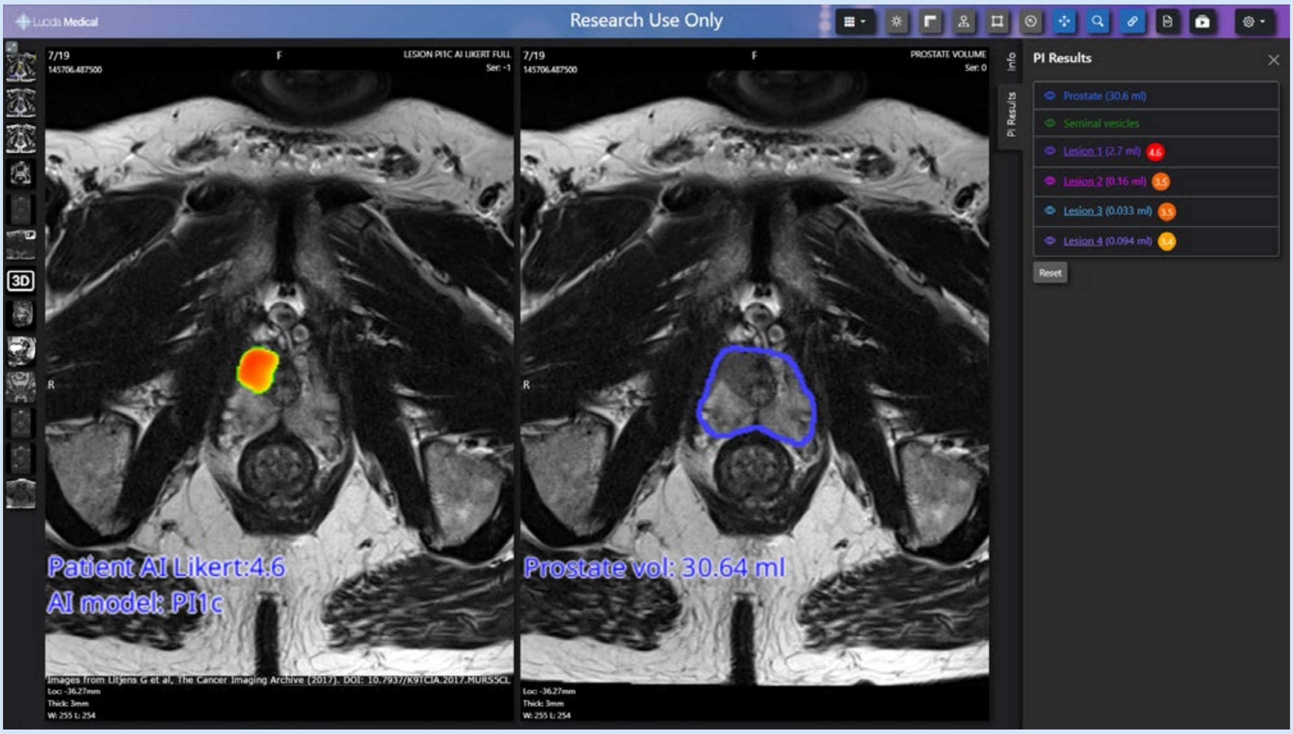
Top tips for involvement in translational research

Tip 7: Invest in support, training and communication tools that help people with lived experience navigate technical and scientific complexity.

Tip 8: Invest in long-term relationships and provide adequate support for all involved.

Tip 9: Involve people with lived experience not just as advisors, but as **co-decision-makers** throughout the research funding and design process.

Lucidia Medical



Patient AI Likert:4.6
AI model: PI1c

Prostate vol: 30.64 ml

PI Results
- Prostate (30.6 ml)
- Seminal vesicles
- Lesion 1 (2.7 ml) 4.6
- Lesion 2 (0.16 ml) 3.5
- Lesion 3 (0.033 ml) 3.5
- Lesion 4 (0.094 ml) 3.4

Images from Litjens G et al, The Cancer Imaging Archive (2017). DOI: 10.7937/K9TCIA.2017.MURS5CL

Lucida Medical develops software tools using AI and MRI, to support cancer screening, diagnosis and management. Lucy Davies is VP Clinical.

Why has Lucida Medical involved people with lived experience in translational research?

The NHS currently struggles to deliver the prostate cancer pathway, with delays occurring at every stage. Lucida Medical wants to speed up the pathway by using AI to ensure that men receive a diagnosis more quickly. They wanted to understand what people with lived experience of prostate cancer think about the use of AI to support the prostate cancer pathway and to explore the perceived opportunities and challenges a one-stop clinic for MRI and biopsy may present for patients.

How are people with lived experience involved in translational research?

Lucida Medical worked with Macmillan Cancer Support to run online focus groups and surveys to address these questions.

What are the challenges?

Most medical device companies want to co-design with patients and the public but don't always know how to approach this

What has the impact been so far?

Lucida Medical found the feedback from people affected by prostate cancer very helpful. People talked about the importance of speed of diagnosis and of good communication. They stressed that AI should be a tool to support clinicians.

LUCIDA
Medical

Top tips for involvement in translational research

Tip 10: Charities can facilitate translational research by helping to build trust with the community.

Tip 11: When introducing new technologies, especially AI, explicitly position them as tools that support clinicians, not replace them.

Tip 12: Design involvement around real concerns and priorities voiced by people with lived experience, such as speed of diagnosis, communication, or care experience, not just technical features.

Duchenne Muscular Dystrophy

Duchenne muscular dystrophy (DMD) is a progressive disease which is usually diagnosed in boys between the ages of 3 and 6. Emily Reuben OBE is the co-founder and CEO of Duchenne UK. Her eldest son lives with DMD.

Why did Duchenne UK choose to get involved in translational research?
Duchenne UK is committed to ensuring that people affected by DMD are represented in all decision-making processes, as they believe that only individuals with lived experience truly understand the daily realities and needs of patients. The charity wants to speed up research that may lead to a cure or treatment, so they have focussed their research funds on translational research. They have also set up a registry of people with DMD.

How are people affected by DMD involved in translational research?
People affected by DMD are involved in a wide range of translational research studies, including those looking at drug development.

What has the impact been so far?
The involvement of Duchenne UK and people affected by DMD has significantly affected translational research. In addition to funding a large number of research studies, there has been impact on drug development, patient information and trial design. Duchenne UK has been critical in understanding a new phase of DMD and in understanding how many people living with DMD are also neurodiverse. This understanding has affected the design of translational research studies.

Top tips for involvement in translational research

Tip 13: Anchor funding and research strategies in the lived experience of patients to ensure that work focuses on what matters most to those affected.

Tip 14: Use involvement to uncover less visible or poorly understood aspects of living with the disease, such as cognitive and behavioural impacts, as, once understood, these can fundamentally reshape study design.

Tip 15: Pair meaningful involvement with targeted research funding to amplify your ability to shape translational research and ensure rapid progress.

Snapshot examples

Some of the participants at our event also shared their experience of involving people with lived experience in translational research:

Diabetes UK funded four Translational Programme Grants in 2024 through the Type 1 Diabetes Grand Challenge partnership (Steve Morgan Foundation, Diabetes UK and Breakthrough T1D). As part of the application process, it was a mandatory requirement that researchers include a named PPIE Co-Applicant - a person affected by type 1 diabetes who is embedded in the research team. Applicants had to clearly detail their involvement in the programme, how they would be supported, and include a suitable budget for PPIE activity costs, which was then reviewed by the Expert by Experience Grants Advisory Panel. Since the grants were awarded, the PPIE Co-Applicants have been working closely with the research teams to lead on PPIE activities.

Debra UK ensures meaningful involvement of individuals with lived experience in its **research funding process**. This includes participation in **application clinics** that support researchers in preparing strong proposals, as well as a **structured expert-by-experience review process** that helps guide funding decisions to ensure they reflect the **priorities and needs of the EB community.**

Heart Research UK runs ‘surgeries’ where people affected by heart disease work with translational researchers online to help strengthen their funding application and ensure that the proposed study is relevant and will benefit people living with the condition. These surgeries have proved to be very helpful, with one researcher commenting “The meeting was very useful and positive, and it was great to work with the enthusiastic patients you kindly put us in touch with. The patients were an absolute pleasure to work with, shared valuable insights and knew the questions to ask based on their experiences and treatment of their condition. The patients behaved like critical friends, so fantastic and generous with their feedback. They helped us identify and explore barriers to the research that we had not yet considered, to better shape and strengthen our proposal.”

MQ Mental Health Research is a global mental health research charity that funds and supports high-quality, interdisciplinary research to better understand, treat, and prevent mental illness. Funding calls at MQ are co-designed with lived experience experts (LEEs), who help set research priorities, sit on funding committees and review proposals alongside academic reviewers, thus ensuring robust Patient and Public Involvement and Engagement (PPIE) is a key assessment criterion. This approach has led to 75% of MQ-supported studies involving lived experience -compared with 61% in researchers’ previous work, with 81% of researchers saying it made their research more valuable, 96% reporting it improved their work, and 92% planning to include PPIE in future studies. When partnering with academics on research projects, MQ through its Lived Experience Research Network (LERN) with over 450 members across 50 countries, involves LEEs at every stage of research. This is from design to delivery and dissemination, shaping patient-facing materials, joining governance structures, and contributing as speakers and panelists at scientific events. MQ supports effective collaboration through training for both researchers and LEEs, transparent and timely payment, clear communication, reasonable adjustments, and an open feedback loop, resulting in more relevant, inclusive, and impactful mental health research.

MS Society’s Octopus clinical trial platform for progressive MS has involved people affected by MS from the very start. The PPI contributors have played a meaningful role from early design to delivery of this translational research.

People with lived experience continue to help selection of new treatment arms for testing and are partners in planning for sustainability through industry involvement in the platform. Their research strategy and funding decisions are based on consultation with both researchers and the priorities of people affected by MS.

MS Society patient involvement group: (Rebecca Cresta Photography)

Ovarian Cancer Action (OCA) supports translational research by funding the critical steps that move discoveries from the lab towards real-world benefit. The OvarianVax project builds on over 10 years of OCA-funded research into how ovarian cancer starts and how the immune system could stop it. Now, working alongside Cancer Research UK, we're funding the next phase: designing and testing a potential vaccine to prevent ovarian cancer. This includes developing the delivery system and refining the vaccine's immune response. OCA is also costed into the project to lead the patient involvement workstream for the vaccine development, to ensure women's voices shape the research as it moves closer to clinical trials. Professor Ahmed, who leads the project at the University of Oxford, said: "Ovarian Cancer Action's support has been vital in embedding patient involvement right from the start. Their leadership in this area has helped us design a vaccine project that reflects the needs and priorities of the women it's meant to protect, making the research stronger, more focused, and ultimately more impactful."

Parkinson's UK and its Virtual Biotech (VB) international drug discovery and development programme in collaboration with Parkinson Foundation are deeply committed to ensuring that people with Parkinson's (PwP) are central in driving their initiatives. This commitment goes beyond clinical trials, as they actively seek and incorporate the views of individuals affected by Parkinson's across various aspects of their research and development efforts. By gathering these invaluable perspectives, Parkinson's UK and VB shares them directly with partner biotech companies and specialized scientists and clinicians. This approach supports and guides research teams, allowing them to collaborate to deliver treatment faster and develop solutions that are truly meaningful and relevant to the PwP community.

Prostate Cancer Research (PCR) Through PCR's multi-modal data platform Prostate Progress, PCR are offering a new clinical trial recruitment and feasibility service for industry partners. PCR will help identify and engage eligible patients, empowering them with the information they need to make informed choices about their treatment. PCR's patient-reported data helps map inclusion and exclusion criteria, acting as a pre-screen to match the right patients to the right trials. In the next phase, they'll incorporate linked clinical data (with consent) to further refine targeting and improve trial efficiency.

Prostate Cancer Research: Billy a supporter of PCR's patient involvement work

What are the challenges to involving people with lived experience in translational research?

The process of involving people with lived experience in research, and of getting involved in research if you have lived experience, is not without challenges. Some challenges relate to the involvement of people with lived experience in any type of research, for example:

Researchers do not always appreciate the importance of involving people with lived experience at an early stage.

Involvement is time consuming and resource intensive.

There is often no funding available to involve people, especially at the pre-application stage.

Different stakeholders have different expectations.

Involvement can be tokenistic.

But there are also some specific challenges that relate to involvement in translational research. These include:

- The complexity of the language that is often used.
- Research involving animals can cause concern for some people with lived experience.
- Researchers who carry out translational research may be less familiar with involvement and may not have the skills to involve people with lived experience meaningfully – this includes the ability to communicate in plain language.
- It can be hard to find people with lived experience who want to be involved in translational research.
- There are few visible examples of involvement in translational research, so it's hard to imagine what 'good' involvement looks like.
- For charities who want to support the involvement of people with lived experience in translational research, it can be hard to find researchers who are doing this, especially in small and medium sized companies.
- Many people at our event felt they lacked the confidence to act as intermediaries and knowledge bearers.

Our event aimed to begin thinking about how we could address the challenges specific to translational research.

Priorities for future action and next steps

Participants at our event identified a number of priorities for future action, which they hoped would help us to begin to address the challenges outlined above. These are the top 10, in order of priority:

1. **Develop 'best practice guidance' on involvement in translational research, including case studies and templates**
2. **Develop better ways of talking about what translational research is and what it involves, including what to expect, how to manage expectations, and possibly an online hub/glossary**
3. **Develop and offer training for PPI leads/research managers to facilitate conversations about translational research**
4. Develop and offer training for people with lived experience to support them to be effectively involved in translational research
5. Set up one big involvement network of people with lived experience that all charities could access
6. Set up 'speed dating' activities that bring translational researchers, small and medium sized companies, charities and people with lived experience together to talk about translational research priorities and plans
7. Help translational researchers to communicate in plain language and explain success measures, technicalities etc
8. Work together to involve more people with lived experience in translational research, and especially to involve a more diverse range of people with lived experience + diverse people
9. Bring together insights that have already been gathered from people with lived experience that are relevant for translational research and share them with translational researchers
10. Utilise target product profiles[2] as a way to meaningfully involve people with lived experience in translational research

Our next step is to bring together a working group to take forward the top three priorities in this list – in bold above.

Bec Hanley, CRIG
Sonja Lawrence, Prostate Cancer Research and TAR
Natasha Ratcliffe, LifeArc and CRIG
Sally Spawforth, Heart Research UK and CRIG
Jayne Spink, Prostate Cancer Research and TAR

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[2] | Target product profiles are documents that describe the desired characteristics of a product. They are often used in health research. They specify the intended use, target populations, and desired attributes of products, and can be used for medicines, vaccines, diagnostic tools, and medical equipment. They can support evidence generation for regulatory submissions and ensure products meet public health needs.

Attendees

Name	Organisation (or affiliated)
Catherine Bailey	Anthony Nolan
Gemma Pugh	Anthony Nolan
Sarah Hartwell	Association of Medical Research Charities
Simon Turpin	Association of Medical Research Charities
Anna Goodman	Asthma and Lung UK
Priyanka Punja	Asthma and Lung UK
Bethan Davies	Blood Cancer UK
Katie Musialowski	Bowel Cancer UK
Karen Noble	Brain Tumour Research
Philip Scard	Brain Tumour Research
Sarah Berry	Breakthrough T1D
Maddie Bonser	Breakthrough T1D
Marilia Ioannou	Breast Cancer Now
Ben Morrison	Breast Cancer Now
Lisa Bates	British Heart Foundation
Liane Hazell	British Heart Foundation
Hana Ayoob	British Society for Immunology
Alison Reeve	Cancer Research UK
Katie Le Blond	Cardiomyopathy UK
Sarah Evans	CCLG: The Children's Cancer and Leukaemia Association
Lisa Radcliffe	CCLG: The Children's Cancer and Leukaemia Association
Bec Hanley	Charities Research Involvement Group
Paloma Fernandez	Cure Parkinson's
Claire Walter	Cystic Fibrosis Trust
Abi Witherden	Debra UK
Rachel Jones	Diabetes UK
Chris Littlewood	Diabetes UK

Name	Organisation (or affiliated)
Emily Reuben OBE	Duchenne UK
Debbie Nichol	Event organiser
Helen West	Guts UK
Sarah Delaney	Health Research Charities Ireland
Sally Spawforth	Heart Research UK
Jo Henderson	Kidney Research UK
Mary McCaul	Kidney Research UK
Natasha Ratcliffe	LifeArc
Lucy Davies	Lucida Medical
Lesley Booth	MQ Mental Health
Parisa Mansoori	MQ Mental Health
David Coutts	MS Society
John Copier	Muscular Dystrophy UK
Amy Muggeridge	NIHR
Faye Hobbs	Ovarian Cancer Action
Nikul Bakshi	Parkinson's UK
Ana Mora	Parkinson's UK
Sonja Lawrence	Prostate Cancer Research
Jayne Spink	Prostate Cancer Research
Ralph Holme	RNID
Julia Clark	Sands
Bhavna Tailor	Stargardt's Connect
Neelam Kaur	Stroke Association
Annabel Wright	Stroke Association
Rachel Roberts	The Brain Tumour Charity
Denise Robertson	The Brain Tumour Charity
Rosie Cockroft	The Urology Foundation
Clare Farmer	Versus Arthritis
Gemma Winsor	Versus Arthritis
Sanjay Thakrar	Vivensa Foundation