Public partnership showcase

Case studies from those working with public partnerships to help share learning on two national improvement areas: **Equality, Diversity & Inclusion** and **Impact & Learning**

NIHR Centre for Engagement and Dissemination

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The Regional to National Public Partnership joint working pilot

On 16 February 2022, a mix of 104 public contributors and those working with Public Partnerships came together in a virtual event to discuss how to work better together.

The aim of the pilot event was to:

Understand and see the contribution made to the national improvement themes

Enable cross-NIHR learning

Improve support and feelings of connectedness

Create a safe space for sharing

Create opportunities to showcase small successes, and strengthen knowledge and confidence

What we did

What are the national improvement areas?

You can read more about the five different national improvement areas **here**.

Thematic 'show and tell'

A key aim of the event was to enable shared learning and create an opportunity to showcase successes in a thematic 'show and tell' session.

The session was structured around two of the national improvement areas: **Equality, Diversity and Inclusion** and **Impact and Learning**. Prior to the event, participants chose which theme they wanted to focus on, to enable shared learning among those with similar interests.

The thematic 'show and tell' centred around individuals sharing their experiences related to the group's theme and national priorities. This document outlines a few examples presented by participants, and aims at showcasing a few successes to inspire others working with public partnerships.

Practice share session: thematic show and tell

Participants were asked to reflect on the following questions on their chosen national improvement area:

- Have you tried something new?
- Have you moved something forward or succeeded in something?
- What did you learn?
- What impact did it have?
- How do these relate to national priorities?

At the event, they shared insights and learning with each other.

Case studies: Equality, diversity and inclusion

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National improvement area: Equality, diversity and inclusion

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Equality, diversity, and inclusion is one of the five national improvement areas for public partnerships. Below is a description of what this improvement area means and what national priorities sit underneath it.

Equality, diversity and inclusion

- Ensuring we are working with a wider range of people, through inclusive approaches
- For everyone to feel able to shape health and care research in ways that work for them

National priorities:

1. Providing sufficient funding and resources that support long-term relationship building with communities and sustained connections

2. Investing in underserved communities, working in partnership with and supporting community groups, and having community champions work within their own communities

3. Taking time to really understand the barriers to involvement and participation for public contributors and investing in actually overcoming them

Case studies: Equality, diversity and inclusion

Key learnings for running a co-development panel:

- The meeting should feel like a safe space where members can be open and honest in sharing their views and experience.
- If the panel is run online, no one should be excluded because of the technology.

Case study 1: Co-development panel

A co-development panel was set up by a team with the aim of including a more diverse range of views in public and patient involvement (PPI). Eleven people from a range of backgrounds, ages and genders, were recruited to the panel using social media.

Due to the Covid-19 pandemic, the panel had to meet online. To adjust to this way of working and ensure trust between members, the panel spent extra time as a group working to develop their connection, using methods such as ice-breakers and scheduling opportunities to chat as a group.

The panel are now viewed as essential research partners who are not afraid to be open and honest with their views. They have been offered positions on new projects and have plans to expand their membership.

This example was provided by a Patient Partner.

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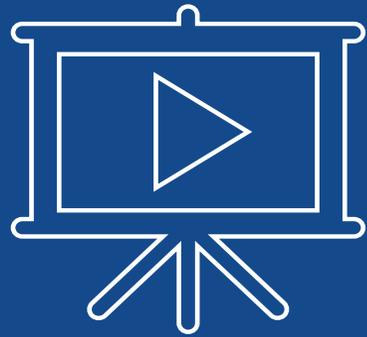
Case study 2: Alternative formats for participant information sheets

This case study describes the impact that alternative forms of communication can have in tackling some of the challenges of traditional participant information sheets. One contributor observed that participant information sheets were often not effective in explaining important information about research to potential participants.

It was found that the information shared in the participant information sheet, including that around consent, was often not clearly understood, leading to some people not being accepted onto trials.

To tackle this, a team created a short video explaining the important information in a way that was easily accessible for participants. The video could be adapted to the needs of different communities or have subtitles added.

The video provides greater consistency and improves participant understanding of research, including the process, outcomes and consent. The video aims to improve participation in clinical trials and outcomes for patients.

Do you want to know more?

Contact Anne Deverell, Public Contributor, anne52.devrell@gmail.com

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Key learning:

Face-to-face community-based activity which is led by local volunteers is a successful way to inform and engage underserved communities in health and care research. Volunteers should be trained and supported to work in their communities.

Case study 3: Volunteers bringing communities and research closer together

To increase equality, diversity and inclusion, a team of volunteer Research Champions took part in an underserved community engagement pilot. The purpose of the pilot was to upskill and support existing community volunteers to share and inform the local community about the value of health and care research. The team was recruited from a regional group of volunteer Research Champions, who are broadly reflective of the ethnic minority profile of the region as well as gender and age profiles.

With the work of local volunteers across three community groups in deprived areas, the engagement has led to the development of a community action plan. The plan is shared with the local community to increase awareness of research, it's benefits and how to get involved.

Do you want to know more?

Contact Evie Chandler, Patient Public and Carer Involvement and Engagement Officer, NIHR CRN, evie.chandler@nihr.ac.uk

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Read more here:

Visit the Patient Led Research Hub by clicking **this link**.

Case study 4: Patient-led research

The Patient Led Research Hub (PLRH) was established by members of the University of Cambridge and Cambridge Biomedical Research Centre to support patient-led research. The PLRH works directly with patient groups and charities to co-produce healthcare research that matters most to the people it impacts.

This method of co-production has been well received by patient groups, charities, and the wider research community. It's evidenced that co-produced, patient-led research is competitive and rigorous, and also provided patient groups and charities a platform to be better heard within academic and medical communities.

Key learning on co-produced research: Co-produced research has longer timescales than other forms of research. There is ongoing learning on how to be more efficient, including developing templates and guidance which can be drawn upon.

Do you want to know more?

Contact Laura Cowley, Research Lead, Patient Led Research Hub, lbm28@cam.ac.uk

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Read more here:

Learn more about what the NIHR is doing to promote race equity in health research by clicking **this link.**

Case study 5: Tackling race equality in health research

A team has developed an external Race Equality Public Action Group to improve inclusion of racially marginalised groups. The group provides direct and honest insight on how the research community can promote better racial equity in health and care research.

The group meet regularly with the research community. Their goal is to help shape the health research agenda to include work that will inform how to best overcome racial disparities in health outcomes.

From the group, researchers have learnt about the scepticism that exists in racially marginalised communities about the equity of medical research. The Group has developed a Race Equality Framework, which is being piloted with 16 research organisations to help increase inclusion in health research.

Do you want to know more?

Contact Katie Cook, Senior Programme Manager and Fay Scott, Senior Public Involvement Manager, repag_enquiries@nihr.ac.uk

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Read more here:

- [Collecting the views of the public through the multiverse lab](#)
- [Multiverse lab community tour](#)
- [A journey into the multiverse lab](#)
- [Multiverse lab - an interactive online experience](#)

Case study 6: Multiverse lab of voices

Working with the creative industry, a team has created a record of communities' voices in what has been called the Multiverse Lab. The lab's purpose is to make sure that the voices of the public, including those who might not traditionally have a space in public engagement, are heard when thinking about the future of health and care research. The project involved asking people to record a short message and answer the question: "What is the health and social care research breakthrough you would like to see in your lifetime?".

The project reached a range of communities through visiting high streets, community centres and festivals. The team also developed an interactive website, shared via social media and mailed to specific community groups. To capture even more voices, the team ran in-person and Zoom socials for targeted community groups, as well as open public sessions where people could share their views and experiences.

The project has led to a bank of honest and personal responses from communities about a range of health and care issues. The space and opportunity to share views and experiences has strengthened relationships with different community groups and resulted in a better understanding of the barriers to involvement and participation faced by the public.

Do you want to know more?

Contact Rachel E Dickinson, Ph.D., Research and Development Study Manager, rachel.dickinson2@newcastle.ac.uk, or Kasia Kurowska, Patient and Public Involvement and Engagement Manager, Kasia.Kurowska@newcastle.ac.uk, NIHR Newcastle In Vitro Diagnostics Co-operative

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Key learning:

Public involvement had the best results when a relationship was formed between researchers and contributors. This requires investment in time and resources to develop a mutual trust between the two.

Case study 7: Working with community organisations

Working with small local community organisations, a team increased diversity in their Public Advisory Network and provided ethnically minoritised communities with increased opportunities to participate in research. The team worked with community representatives, young people, faith leaders and members of the public to identify issues which matter most to them.

This work has led to a better understanding of PPI in ethnically minoritised communities. It has enabled a more diverse range of the public to get involved in research and improved researcher's knowledge on the type of issues facing communities. This has resulted in better resourcing of funds to tackle these needs.

Do you want to know more?

Contact Dr Felicity Shenton, Public Involvement & Community Engagement Manager, NIHR ARC, felicity.shenton@cntw.nhs.uk

Case studies: Equality, diversity and inclusion

Show and tell snapshot

Coffee mornings or community events to build trust and relationships

Co-production groups involved from the very beginning

Be innovative and creative when seeking feedback from contributors

Be creative in methods of engagement

Sharing case studies that reflect diversity

Advertise opportunities in formats that are attractive for diverse communities – language and animations

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Case studies: Impact and learning

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National improvement priority area: Impact and learning

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Impact and learning is one of the five national improvement areas for public partnerships. Below is a description of what this improvement area means and what national priorities sit underneath it.

Impact and learning

- Ensuring we can learn from what works and what doesn't
- Having approaches to help us capture the difference and impact of our partnership working

National priorities:

1. Developing a shared understanding of what we really mean by 'impact', which accounts for the nuances of partnership working, and the longer term, more intangible benefits, and providing guidance and expectations on how to capture this

2. Providing training and easy tools to collect feedback, capture impact and share learning, which is focused on improving rather than justifying the value of partnership working

3. Working with public contributors to define what impact looks like to them and to understand their journeys, and in doing so, identifying and improving the process of partnership working from their perspective

Case studies: Impact and learning

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Key learning from working in partnerships:

Working in effective partnerships – in this case with finance managers – led to impact and meaningful change.

Case study 1: Innovating PPI payments

A team has worked with funders and government bodies across the UK to address issues and barriers around payment for involvement in research.

The team used an original, new approach, engaging with finance managers to work on the employment status and categorisation of public and patient contributors. The cross-nation approach that was taken was felt to be innovative and was used with the intention of bringing about the most impact across the UK.

This work is ongoing but so far the project has demonstrated leadership, innovation, and effective engagement with partners. Through productive engagement with HMRC the team hope that the work will lead to a simplification of the payment process for involvement in research.

Do you want to know more?

Contact Silvia Bortoli, Senior Public Involvement Manager, NIHR CED, silvia.bortoli@nihr.ac.uk

Case studies: Impact and learning

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Key learning:

- The team found that people do not always recognise experiences as learnings and there was a lack of value placed on what people have learnt.

- Learning from what has not gone well are some of the most valuable lessons.

Case study 2: Reflecting on learnings

To develop their system of feedback, a team set up a process of collecting learning through three routes: PPI network (all staff working in PPI), PPI champions, and public contributors.

Insights from the learnings have helped to inform training programmes, support materials, case studies and have informed changes in practice. The feedback received through the three routes has been used to promote things that went well, or learn from things that were not so effective. To facilitate a space where people felt comfortable sharing experiences – particularly those that were less successful – it was important to foster a culture of trust between members.

From their work, the team discovered the value of talking about experiences in PPI – both positive and negative – to help modify and improve practice. This system of feedback is an ongoing process which is open to all those involved in PPI.

Do you want to know more?

Contact Georgina Norris, Patient and Public Involvement/Engagement Coordinator, gan23@medschl.cam.ac.uk

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Feedback guidance:

Click **this link** to find a co-designed guidance for feedback.

Click **this link** to find guidance from NIHR.

Click **this link** for an article on health expectations.

Click **this link** for an article on research involvement and engagement.

Case study 3: Co-designing feedback and guidance

A team has been working with Patient and Public Groups in the East of England to co-design new feedback processes and guidance. Their aim is to improve feedback given from researchers to public and patient contributors.

To have the greatest impact, the team needed to ensure PPI leads, contributors and researchers had a trusted, mutual relationship. It was important that each person's views were treated with equal respect and importance and that a common understanding was established for all to work together to understand the impact of public and patient involvement.

An evaluation using a before and after survey found that the work has improved the feedback process. Additionally, the co-designed guidance has been used and recommended on a number of national and international websites.

Do you want to know more?

Contact Elspeth Mathie, Reader in Health and Social Care Inclusion, NIHR Applied Research Collaboration East of England, co-lead Inclusive Involvement in Research Theme, University of Hertfordshire, e.j.mathie@herts.ac.uk

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Case study 4: Events to promote involvement in research

Working with residents, staff and a Public Research Champion, a team have been aiming to raise awareness of health and care research amongst residents of a retirement village. The team hosted an 'I Am Research' event for residents with speakers, interactive displays and performances. Interactive displays highlighted current research such as advancements in treating diseases like rheumatoid arthritis, dementia, stroke, and eye conditions.

As a result of the event, the team developed a checklist, with top-tips for hosting research awareness events in non-NHS settings. The guidance was informed by feedback from both attendees and organisers of the event.

The event led to an increase in resident interest in participating in research, and has sparked interest in further similar events. Residents and staff are keen to work together to plan future events that build on this success.

Event checklist:

✓ Event is accessible and meets the specific needs of those attending

✓ Speakers and contributors are fully briefed on the event

✓ There is clarity on the purpose and audience of the event

Do you want to know more?

Contact Mary-Anne Darby, Head of Patient and Public Involvement and Engagement in Research, LCRN West Midlands Core Team, mary-anne.darby@nihr.ac.uk

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Early findings from the Involvement Alliance:

The project is still in the early stages but the team are already beginning to build their understanding of the range of engagement and involvement activities in Wales.

Case study 5: Involvement Alliance

A team has developed an Involvement Alliance to bring together public involvement leads from universities, health boards and social care practitioners in Wales. The aim is to coordinate public involvement activities across the funded community, develop a consistent approach to involvement, and share and promote news and best practice among the research community.

To understand impact, the team are collecting feedback using the UK Public Involvement Standards, from which the learnings will be shared with the wider community.

Early findings have shown differences in capacity available to support public involvement in the research community, highlighting the need to capture impact, training, support and practical tools which can be applied across the community.

Do you want to know more?

Contact the Public Involvement Team at Health and Care Research Wales, research-involvement@wales.nhs.uk

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

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Do you want to know more?

Contact Linda von Nerée, Patient and Public Involvement and Engagement Lead, NIHR BTRU in Stem Cells and Immunotherapies at UCL, l.vonneree@ucl.ac.uk

Case study 6: Patient and Public Partnership working in lab-based and early clinical research

A team including researchers and public and patient members set out to explore how PPI can be better included in early research for new potential treatments. The team developed a structure for partnership working by building confidence and support for researchers and patient and public members to better understand each other's purpose and work. The team set up a lived experience group who met with researchers in an introductory meeting to build a trusting relationship and better understand the research projects.

The team used easily accessible information such as documentaries to help develop the patient and public members' knowledge of the research. Working with a lived experience group helped researchers gain better insight into patients concerns, hopes, and needs.

PPI members and researchers worked collaboratively to identify PPI elements in their work and consider ways to tackle PPI challenges. The team co-designed a workshop inviting PPI members and researchers to look specifically at PPI in early research. Having funding from NIHR, support from partners, and a PPI lead helped researchers gain insight into the benefits of partnership working. This work has been described as 'transformative', leading to wider discussions and support requests, and training being offered to wider audiences.

Case studies: Impact and learning

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Key learning:

The team found that participants were generally happy to give feedback after events. Participants provided both positive and negative comments which could be used to improve participant experience of events.

Case study 7: PPI feedback forms

In this case study, a team implemented feedback forms for participants to complete after attending an online PPI event. The purpose of the evaluative feedback forms were to provide researchers with feedback from events from public and patient members. This would allow them to gain a better insight into the experience of public and patient contributors and strengthen the relationship between the two.

Team reflections on the effectiveness of the feedback forms acknowledged that researcher feedback would also be valuable. The team felt that sharing researcher experience with public and patient contributors would be more effective in learning, would be less 'transactional' and would allow researchers to thank contributors for their involvement. It would also be a valuable measure of how the event ran for public contributors that attended.

Do you want to know more?

Contact Sue Watson, Chair of the PPIEP Core Group at Leeds Biomedical Research Centre (BRC), watsonshuk@yahoo.co.uk

Case studies: Impact and learning

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Key learning from a PPI and researchers 'drop-in' session:

- There is space to be brave and innovative
- Researchers are keen to embed impactful PPI within their research and are open to working with contributors to seek the best methods of involvement.

Case study 8: A safe space for learning

This case study describes the plans of a team to pilot an informal PPI and researchers 'drop in' session. The session aims to bring together researchers and PPI contributors in an informal, safe space to develop and strengthen their shared relationship.

The Forum will allow PPI contributors to share their experiences, ideas and opinions on PPI-related aspects of research in a two-way conversation between researchers and contributors. It will create a space where researchers can ask questions to help evolve their practice in improving and strengthening the way PPI is used throughout the project lifecycle.

The team implementing the pilot hope that this will contribute to meaningful, respectful, transparent and tailored communication and that PPI contributors will feel better valued and appreciated. As a result there are expectations that PPI contributors might increase their involvement and commitment to PPI. There are plans to hold the first Forum meeting in 2022.

Do you want to know more?

Contact Abi Dennington-Price, Education and Research Patient & Service User Representative, abigail.dennington@btinternet.com

Case studies: Impact and learning

Show and tell snapshot

Training staff with PPIE responsibility

Use case studies to help staff understand the impact of their work

Co-produced research between patient and public contributors and researchers

Consult with staff to identify areas where they would most value training and support

Learning and sharing webinars and lectures

Utilise reporting systems and feedback forms

Version control

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