

**NIHR Biomedical Research Centre: Oxford and Clinical
Research Facility: Oxford (NIHR BRC/CRF: Oxford)
Patient and Public Involvement, Engagement and
Participation (PPIEP) Impact Report, 2022-2026**

Patients, the public and researchers working together to improve research

September 2026



The Oxford Patient and Public Involvement, Engagement and Participation (PPIEP) team

The NIHR BRC/CRF: Oxford involves patients, families, carers and the public from diverse communities as valued research partners, improving health and wellbeing for all.

Welcome to the NIHR BRC/CRF: Oxford PPIEP Impact Report for 2022-2026, which showcases the impact of patients and members of the public working together with researchers.

The BRC/CRF PPIEP team supports researchers, patients and the public to embed patient and public experiences in research across our 15 research themes. This ensures that research is relevant, inclusive, and meaningful to the people it is intended to benefit.

The PPIEP team provides accessible and inclusive opportunities for patients and the public to take part in research throughout the research lifecycle, with a special focus on welcoming people from under-served communities.

The team delivers training for researchers and offers guidance and practical support to ensure their studies involve and engage the public.

The team researches and evaluates the impact of public involvement to improve and highlight best practice in PPIEP. We publish and share our findings.

We collaborate with local and national NIHR partner organisations, academic institutions, the NHS, charities and community groups to share best practice, knowledge and resources for effectively involving the wider community, developing engagement opportunities and strengthening partnerships.



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NIHR BRC/CRF: Oxford PPIEP Impact Report, 2022-2026

1.0 Working with Patients and Public Partners



1.1 Patient and public partnership groups

The NIHR BRC/CRF: Oxford supports patient and public partnership groups who, working with the core PPIEP team, provide support and advice to researchers. Our themes also have condition-specific PPIEP groups focusing on, for example, vaccines, cancer, diabetes, musculoskeletal conditions and many more. [A list of PPI groups can be viewed here.](#)

NIHR BRC/CRF: Oxford Patient and Public Advisory Group

The NIHR BRC/CRF: Oxford Patient and Public Advisory Group comprises patients, carers and other members of the public representing different themes of the BRC. The group aims to facilitate patient and public involvement across the themes and to offer support, advice and training, working in partnership with researchers to identify and maximise opportunities for meaningful involvement across BRC Oxford themes and the CRF Oxford.

NIHR BRC/CRF: Oxford Diversity in Research Group and Diversity Network

The Diversity in Research Group is a patient and public partnership group who aim to make involvement in health research more engaging to diverse communities, especially those not usually involved. The groups meets online and in person.

Researchers work with the groups to discuss their research and ensure it is accessible to a wide and diverse audience. The members of both the Diversity in Research Group and Diversity Network are from communities under-served in research.



1.2 Diversity in Research Group Community Charter

Eighteen members of the Diversity in Research Group and eight staff members were joined by a diversity and inclusion facilitator, Matt Jacobs, from Wide Open Voices to co-develop the group's Community Charter.

The Community Charter ensures that everyone feels safe and confident expressing views in meetings.

Established in 2021, the Diversity in Research Group includes people of different ages, diverse backgrounds and from a range of communities, such as Black African, Black Caribbean, Asian heritage and LGBTQ+. Group members have links, through paid or voluntary work, to a range of organisations, including those that work with refugees and young black mothers. Many of the group members are linked to organisations advocating about and researching health conditions.

Following extensive preparation with members of the group and staff, Matt expertly facilitated a session where people expressed their hopes and fears in relation to being a member of the group. Over the following weeks the group developed a charter, which is expressed in the infographic opposite.

The Community Charter is referenced at the beginning of meetings and can be adapted if needed, in order to respond to the changing needs of the group.

As well as the infographic, there is a script version, both of which are on the Diversity in Research Group web pages.



1.3 Impact projects 2025-2026

Patient and public members work with researchers to make a positive difference to research. Below is a snapshot of some of the projects the Diversity in Research Group and Diversity Network have worked on over the last year.

30+

PPIEP
Projects

27

DiRG and Network
Members involved

70+

Times members involved
in projects over the year.

Trust in data science and patient data

Marketing meets medicine

Advanced care directive

Effectiveness of Covid-19 booster vaccines in the UK

Supporting equality of access to research

Hospital acquired pressure injuries (HAPI)

Supporting frail elderly people in hospital

Reducing the impact of drug shortages on patients

Encouraging research involvement from minority groups with joint/muscle problems

Neuropsychiatric disorders following infection and chronic widespread pain

Life course determinants of cognitive health inequalities in UK adults

Medical service review

Polygenic risk scores (PRS)

Outreach framework project

Role of inflammation in dementia, psychosis, and other brain disorders

Establishing a digital secure data environment for inherited cardiac condition (ICC)

Exploring experiences of current participants in clinical trials

Safety and effectiveness of novel medicines in patients underrepresented in randomised trials

Improving the way we measure depression, using diverse lived experiences

Aggression on mental health wards - a collaborative safety planning approach

1.4 Training and support for patients and public partners

Context: NIHR BRC/CRF: Oxford public partners provide advice, guidance and knowledge to researchers, PPIEP staff and each other. Having heard from public partners that they sometimes find it difficult to speak up in meetings, we have created a series of training sessions and resources to help develop confidence. The training was co-produced and delivered by public partners. Further training has been co-produced on Reviewing Plain English Summaries.

Collaborators: Members of the PPIE advisory group and Diversity in Research Group co-produced online PPIEP training for patient and public partners.

What we did:

NIHR BRC/CRF: Oxford public partners developed a PPIEP Welcome Guide for new or curious public partners. We deliver:

- Induction training, which explains how PPIEP influences all areas of a research study in theory and practice.
- Making Your Voice Heard as a public partner.
- Reviewing Plain English Summaries.

The training sessions were designed by public partners based on their own lived experience as patient and carers, and their extensive PPIEP work in Oxford, the UK and internationally. Initially aimed at Oxford-based public partners this has broadened its reach to include participants from across England.

Train the Trainer sessions have also been provided in order that PPIEP leads in partner organisations can deliver this training with their local public partners.

Post-training evaluation 2025-2026:

95

Attendees at
Webinar: Plain
English Summaries

107

Attendees at
Webinar: Making your
Voice Heard

100%

Attendees reported
feeling more confident
following training.

**Public
partner
presenters:**



Jenny Gould



Magdalen Wind-Mozley



Sue Duncombe



Peter Deussen

“ I have taken a lot from this training and one of the things that stuck with me was knowing that I am not alone in feeling that sometimes I am not able to speak up with topics I am not an expert on, or if there isn't a way for me to interject or join in a conversation. Also, I feel valued that we are treated as a team in this group. ”

PPIEP Partner, Making your Voice Heard, May 2024.

“ The structure was excellent. The slides were very clear, the session was extremely well facilitated. Would firmly recommend to all novice reviewers. ”

Attendee evaluation, January 2026.

2.0 PPIEP Impact Case Studies



2.1 Gonorrhoea CHaNGe study: using public involvement to improve a sensitive research procedure

Context: The CHaNGe study is a ‘challenge study’ which involves healthy volunteers being exposed to neisseria gonorrhoeae, the bacteria that causes gonorrhoea infection, via an intimate procedure. Individuals are also asked to discuss their sexual health and undertake testing for sexually transmitted infections.

Project aim: To involve PPI partners in the study design phase, feeding back on the handling and communication of sensitive information, a demonstration of the inoculation procedure on a model and participant facing study documents.

Researchers: Susanne Hodgson, Vivian Yim, Lizzie Stafford and Ellen Higginson from the Oxford Vaccine Group

Partners: Five public partners assigned male at birth, some of whom had a personal history of gonorrhoea infection.

Impact of partner involvement:

- More acceptable study processes for participants: public partners provided feedback on the acceptability of asking participants to avoid all kissing during the study ‘abstinence period.’ Following this feedback and after reviewing the scientific evidence, the study team removed this requirement. Partners also provided input on researcher questions around confidentiality, NHS record sharing and how we plan to communicate with nominated emergency contacts.
- More user-friendly information for participants: public partners recommended specific plain language adjustments, less-intimidating visuals (photographs/videos rather than illustrations), and to frame the study as ‘familiar and routine’ rather than ‘technical and experimental’.
- More comfortable experience for participants: after viewing the live demonstration, public partners suggested practical comfort measures (e.g. a visible clock, entertainment), staff continuity (where possible) and privacy measures.

“Working with the research team on this study has been informative and I have felt my input to be important, especially so given the sensitive nature of the study topic. I have also thoroughly enjoyed working alongside my fellow contributors, as well as the wider research team.”

Michal, public partner.

“Engaging with our PPIE group brought invaluable lived experience into our research, helping to ensure that the questions we ask, the decisions we make, and the outcomes we pursue are relevant and meaningful to the people they are ultimately intended to benefit.”

Vivian Yim, researcher.



2.2 Medicine meets marketing: co-design of strategies to recruit and retain diverse participants in clinical trials

Project aim: To explore the benefits and challenges of marketing techniques for recruitment and retention in clinical trials using digital and traditional methods.

Researchers: Geil Astorga, supervised by Dr Joanna Crocker.

Partners: Five members of the Diversity in Research Group and Diversity Network.

Impact of partner involvement:

- All sections of the grant application were revised based on public partner feedback to improve clarity, reduce jargon, incorporate bullet points and better articulate outcomes. The application was edited to reflect the comments provided during a meeting and through document annotation.
- The reviewers of the grant are committee members without expertise in the subject area. Feedback from public partners, with particular focus on removing jargon and simplifying unclear sections, contributed to the successful award of the grant in March 2026.

“Working with the public partner group has been valuable in helping us communicate our ideas more clearly and ensuring the work is grounded in real-world perspectives. I look forward to continuing this partnership as we explore the mechanisms of applying marketing to support inclusive participation in clinical trials.”



Geil Astorga, MHS, Doctoral Student
in Translational Health Sciences,
University of Oxford,

2.3 Polygenic Risk Scores (PRS)

Project aim: PRS is a score that looks at someone's risk of developing a condition. Our aim is to explore public views about personal genetic information being used for ill-health prevention.

Researchers: Kathryn Sheridan Clay and Juliette Foulon.

Partners: Four members of the Diversity in Research Group and Diversity Network.

Impact of partner involvement:

- Previous research interviews suggested people were overwhelmingly in favour of genetic tests. However, the discussions with BRC/CRF Oxford public partners meant consequences and concerns were explored, providing a balanced view.
- The public partners positively confirmed the value of the project.
- Advice was given that greatly added value to the recruitment, informed consent process and data collection. This included clarifying its purpose and ensuring understandable content in lay persons terms.
- The group recommended providing more information, signposting resources and improving language to remind people of their autonomy.
- The results led to improvements of the interview guides to help shape patient conversations.
- Suggestions were incorporated into the recruitment materials, supporting the ethics review process.



“ It has been valuable to increase accessibility of research for diverse and underrepresented groups, as well as improve the quality of researchers within and beyond the project. It is very important to have healthcare and services that respect and support the community, and this work helps address existing misalignments. What is working really well, is having small groups for projects as well as information sources that cover basic PPIE for researchers. ”

Kiran, postgraduate clinical medicine student and member of the Diversity in Research Group. She is a co-founder of the 1928 Institute and engages in PPIEP to improve access and effectiveness of emerging research for diverse communities, with particular interest in the South Asian diaspora, carers, and young people.

2.4 Reducing the impact of drug shortages on patients

Project aim: To learn about the experiences and opinions from patients and members of the public. This included reviewing drug shortages, the initial project draft and lay abstract to be submitted for the research grant.

Researcher: Marta Pineda Moncusi.

Partners: Three public partners from the Diversity in Research Group and Diversity Network.

Impact of partner involvement:

- A new group of lithium-based medicines and palliative care medicines were added to the grant proposal as an 'exposure of interest', which are any variables which influence health indicators, to determine safety, efficacy and risk.
- Improvements were made to the readability and understanding of the lay abstract.
- Different characteristics were added in the individuals' evaluation section to improve representation and inclusivity in the research project.
- Patient and public involvement strengthened the research proposal and the committee were happy that this successfully met requirements.



“I would like to convey a huge thank you to the DiR group members for their valuable feedback. It was surprising for me to hear some of the impacts on patients of drug shortages and their candid insights reminded me why I became a researcher.”

Marta Pineda Moncusi, MSc PhD, Postdoctoral Researcher in Health Data, Pharmaco- and Device Epidemiology Group, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford.

2.5 Exploring experiences of participants in clinical trials

Project aims: To improve the overall experience of trial participants at the Experimental Medicine Clinical Research Facility (EMCRF). To improve the current trial participant feedback survey questions and collection methods.

Researchers: Cushla Cooper, Clinical Operational lead, and Angeli Vaid, Research Inclusion Manager.

Partners: Four members of the Diversity in Research Group and Diversity Network.

Impact of partner involvement:

- Partners recognised and highlighted a broader patient journey which begins before patients arrive on site and after their visit, which could affect overall experience.
- Public partners visited the site to gather first-hand experience and insights.
- An improvement plan to make the patient journey easier included:
 - ‘Top Tips for your visit’ e.g. where to find the League of Friends Cafe, or how to access Wifi details and an acronym buster.
 - A ‘How to find us’ webpage along with physical onsite directions.
 - Providing a ‘What to expect when you get here’ page with swipe in/out details and ‘What to expect when you leave’ e.g. discharge summary.
 - Guidelines for creating a broad, digital Patient Journey Map and video, for easy accessibility.
 - The map will aid patients and healthcare teams when scheduling visits and improve the overall patient experience when participating in research.



“ Talking to the public partners was productive and valuable. They definitely gave me some things to think about such as the redesign of the reception and entrance areas and the importance of the welcome experience. This included letting the patient know they are cared for; giving them the time to decompress after the stress of getting here – kindness and a smile – which I think my team are excellent at, but we need to maintain it. They were also happy to review our “confirmation of appointment” email templates, which would be very useful. ”

Cushla Cooper, Clinical Operational Lead, NIHR Clinical Research Facility: Oxford, University of Oxford.

2.6 Laboratory visits: part of the Oxford Cancer Research Buddy Scheme

Project Aim: To facilitate cancer laboratory visits for patient and public partners, increasing understanding of both cancer research and lived experience. By bringing researchers and people affected by cancer together, the project promotes mutual learning, strengthens relationships, and highlights the importance of PPIEP within the culture and practice of cancer research.

Researcher: Alex Colton, 2nd Year DPhil Student.

Partners: Patrick McGuire & Sarah Markham, PPIEP Reps, Catriona Gilmour Hamilton, PPI Manager, Oxford Cancer and with thanks to James Chettle, Post-doc Research Associate, for support in planning the day.

Impact of partner involvement:

- Researchers were introduced to their patient and public partner buddies online prior to arranging a lab visit. During the visit various techniques were demonstrated along with a presentation of the current research project with handouts to explain the role of proteins in cancer genesis – see photo opposite. The group then enjoyed further networking over lunch with the Oncology Department.
- Researchers reported that visits helped improve morale and can bring their research to life by hearing lived experiences. It was also shown to help develop researchers presentation skills to members of the public, outside of the science community.
- Patient and public partners gained insight into the laborious, dedicated and sometimes frustrating realities of cancer research and an understanding of the real value of donating tissue for research.



“Despite having visited many research labs over the years this is the first time I was made aware of the painstaking, detailed process just to get to the point at which the researcher can actually engage with their research question. A fascinating insight.”

“I gained a deeper understanding of the passion and commitment of the researcher - and all the obstacles and uncertainties they face. I hope Alex will take any opportunity that may arise to ask us for any additional help that we may be able to give.”

“I really enjoyed the challenge of explaining my protein work to Sarah and Patrick - and was reminded of how much I know!”

Patient and public partners.

Cancer Researcher.

2.7 Exploring lived experiences of inflammatory arthritis

Project aim: To involve patient and public partners with lived experience of inflammatory arthritis in the design and delivery of the research trial, helping to ensure it addresses outcomes and priorities that matter most to patients. The TaILOR trial aims to study the clinical and cost-effectiveness of a patient-initiated follow-up (PIFU) strategy compared to traditional care pathways in people with inflammatory arthritis treated with long-term immune-suppressing therapies: <https://tailor.oxtru.ox.ac.uk/>.

Researcher: Clinical trial led by principal investigator Professor Laura Coates.

Partners: Four members of the specially recruited patient and public partner group.

Impact of partner involvement:

- Patient and public partners were recruited with lived experience of all three of the most common forms of inflammatory arthritis included within the TaILOR study.
- The partners were involved from the very beginning and were able to input to the shape of the study right through the research cycle, supported by the PI and the Trial Manager.
- Partners contributed considerably to the development of patient and health professional resources for all the study sites and were intrinsically involved in disseminating these materials more widely to all rheumatology units.
- The materials also helped to improve support for all patients moving onto a patient initiated follow up pathway, beyond the trial sites.



“I’ve lived with inflammatory arthritis for over four decades and I am one of four patient and public partners within the study team on the TaILOR Trial. I think I can speak for all four of us when I say we genuinely feel part of the study team and not just a tokenistic group on the sidelines. We also support each other, something that has been particularly helpful when we have been involved on bids for larger studies.. The study team is a pleasure to contribute to, and I feel our contributions have ensured that the trial is really focused on supporting the patients involved as well as possible.”

Ailsa Bosworth MBE, Founder and National Patient Champion, National Rheumatoid Arthritis Society and patient and public partner on TaILOR study.

2.8 Improving diversity and inclusion in inflammatory disease research: A medical service review

Project aim: To improve the diversity and inclusion of patients from underrepresented groups in inflammatory disease research and identify the enablers and barriers to their participation in experimental medical studies.

Researchers: Dr Jacqueline McLean, Qualitative Researcher and Corrine Hendy, PPI Manager.

Partners: Members of the MSR Patient Advisory Group, Diversity in Research Group (DRG) and Kennedy Patient Partner Group (KPPG).

Impact of partner involvement:

- Research instruments such as the participant information sheet, consent forms and semi-structured interview questions have been revised based on partner reviews and detailed feedback.
- Partners will also be taking part in pilot interviews to ensure that interview questions for patients in the main data collection stage of the MSR are sensitively phrased, easily understood and can capture the right data to answer the review questions.



“It has been a pleasure working with our patient partners to champion the involvement of underrepresented groups in inflammatory disease research. They have contributed a wealth of lived experience and constructive feedback to help ensure that people from diverse communities have their voices heard and that no research about them is undertaken without them.”

Jacqueline McLean PhD, Qualitative Researcher and Medical Service Review Co-Lead, Kennedy Institute of Rheumatology, University of Oxford.

2.9 The clinical and cost effectiveness of oral versus intramuscular glucocorticoids in rheumatoid arthritis

Project aim: To hear patient perspectives on the LEADER Trial which explores the clinical and cost effectiveness of oral versus intramuscular glucocorticoids in rheumatoid arthritis.

Researcher: Dr James Bluett, NIHR Regional Development Network, National Specialty Lead for Musculoskeletal and Orthopaedics.

Partner: Sienna Yates, PPIE representative on the Trial Steering Committee.

Impact of partner involvement:

- Patient perspectives were included in discussions about recruitment, participant burden and whether study procedures are practical.
- The partner asked whether the steroid diary recorded side effects as well as adherence, helping ensure the committee considered participants' experiences of taking the treatment.
- Views were explored on extending recruitment and partners supported allowing additional time to review progress if recruitment improved.



“PPI helps the committee look beyond the figures and consider how the trial feels for participants in real life, leading to more balanced, practical and patient centred decisions.”

Sienna Yates, public partner.

2.10 Exploring patient perspectives of the CHILL project for rheumatoid arthritis

Project aim: To hear patient perspectives from the National Rheumatoid Arthritis Society (NRAS) on the CHILL research project prior to launch of the clinical trial which aims to recruit patients with rheumatoid arthritis (RA) and systemic sclerosis.

CHILL PROJECT Clinical Trial details.

Researcher: Gareth Wright, Quell Therapeutics working in partnership with Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford.

Partners: Sharon Harley and Sarah Collins, Involvement Panel member with National Rheumatoid Arthritis Society (NRAS).

Impact of partner involvement:

- All meetings were online to reduce travel costs and accessibility concerns. The partners reported that this was extremely convenient due to mobility concerns and one mentioned they were going through surgery recovery at the time of the project.
- The Patient Information Participation (PIP) documents were reviewed and discussed with the organisers, with careful consideration of the technical details. The partner explained their thoughts on how patients might approach the literature and whether they would find it clear and concise or challenging to understand.

“Sharing personal experiences, concerns and ideas helps make sure the research is not just scientifically useful, but also relevant to the people it is actually about.”

Bridget Bassey, patient advisory group member.



“Contributing to research is a rewarding way to make sense of having an affliction. I might as well use the experience to enlighten researchers and clinicians about my condition in ways which could really make a difference to their work. More important is the thought that it would be truly wonderful if the research led to a treatment that changed lives for the better.”

Sarah Collins, public partner.

“My biography was reviewed by the study organisers and I was successful. I joined the study advisory panel. It was a quick and efficient process from notification of the opportunity to joining the panel.

It was perfectly clear to me that my participation was voluntary and I could withdraw at any time without giving a reason, so this made me feel comfortable to know there would be no issues if I had to withdraw.”

Sharon Harley, public partner.

2.11 EDI Toolkit Project

Project aim: To explore the barriers and solutions for the inclusion of under-represented groups in clinical trials, as part of the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford (NDORMS) and NIHR Clinical Research Facility: Oxford's Ethnicity, Diversity and Inclusion (EDI) Toolkit Project.

Researcher: Sarah Carr, PPI Co-ordinator. Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford.

Partner: Mala, member of the project patient and public advisory group.

Impact of partner involvement:

- The partner contributed written feedback on barriers that may prevent people from under-represented groups from taking part in early-phase clinical research.
- Focus was on plain English communications, neurodivergent accessibility, communication differences, trust, practical access needs and the importance of flexible ways to contribute.
- The partner ensured that the barriers and solutions identified in an evidence review were further developed by integrating patient experience and knowledge.



“ I think PPI makes a real difference because it helps research teams see where information or processes may look clear on paper but may not feel clear, inclusive or manageable to the people being invited to take part. ”

Mala, public partner.

“ While we had an idea of the barriers and solutions from research evidence and existing guidance, our understanding was incomplete without the perspectives of people with lived experience. Through PPI we built a much stronger evidence base to inform the EDI Toolkit. ”

Sarah Carr, researcher.

2.12 Computer-Aided Tracking and Motion Analysis with Ultrasound (CAT&MAUS): Development and Validation of a Novel Joint Assessment System for Orthopaedics

Project aim: To develop a system that can enhance the NHS ultrasound equipment by accurately measuring and visualising the 3D movements of bones and joints, such as the knee.

Researcher: Simon Abram, Principal Investigator, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford.

Partners: Members of the patient and public involvement group.

Impact of partner involvement:

- Partners advised on the language of the Participant Information Sheet to make it more accessible including replacing technical words such as 'outcomes' with more widely understood 'results' and 'problem' to remove possibility of it being seen as negative and judgemental, with 'issue'.
- The experience was explored from the perspective of a patient visiting for a clinical trial. This included describing the process in plain language: the application onto the skin of a cold, colourless gel, which is painless, for example. Partners indicated that this would help manage the expectations of participants so they felt prepared for what would happen at each stage, and would be particularly helpful for those with additional sensory needs.



“My ideas about how to make the language of the Participant Information Sheet more accessible were well received. I suggested giving a clear, simple explanation of what would happen at a visit if someone agreed to be part of this study- what their experience would be, step-by-step. I think this helps ease participant anxiety, and hopefully shows that the researchers are person-centred in the approach to involving people in their work.”

Claire Jowett, public partner.

3.0 Working with Communities

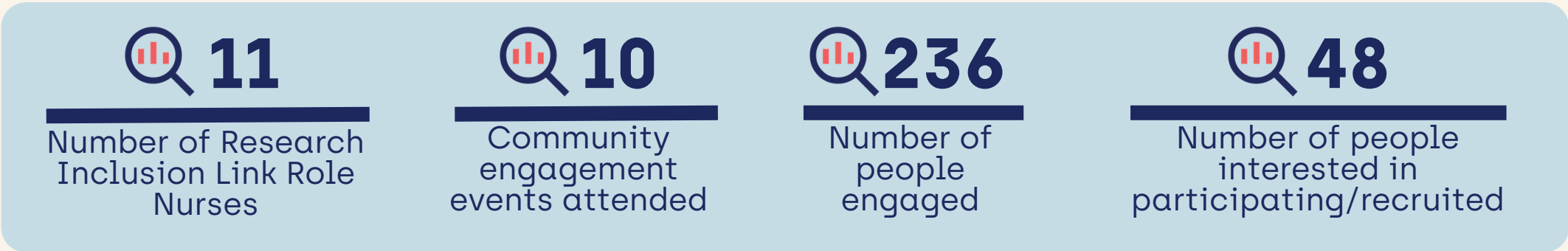


3.1 Embedding inclusive research in our workforce

Pilot aim: To support NIHR strategic areas, the NHS 10-year plan and Thames Valley Integrated Care Board priority areas, and develop scalable, integrated research inclusion practices with the research delivery workforce. Between 2025-26, research nurses were trained to undertake inclusive recruitment and outreach with under-served communities.

Collaborators: University Hospital Southampton NHS Foundation Trust (lead organisation), South Central Ambulance Service NHS FT, Hampshire Hospitals NHS FT, NHS Wessex Cancer Alliance, Oxford University Hospitals NHS FT with NIHR Biomedical Research Centre: Oxford & NIHR Clinical Research Facility: Oxford.

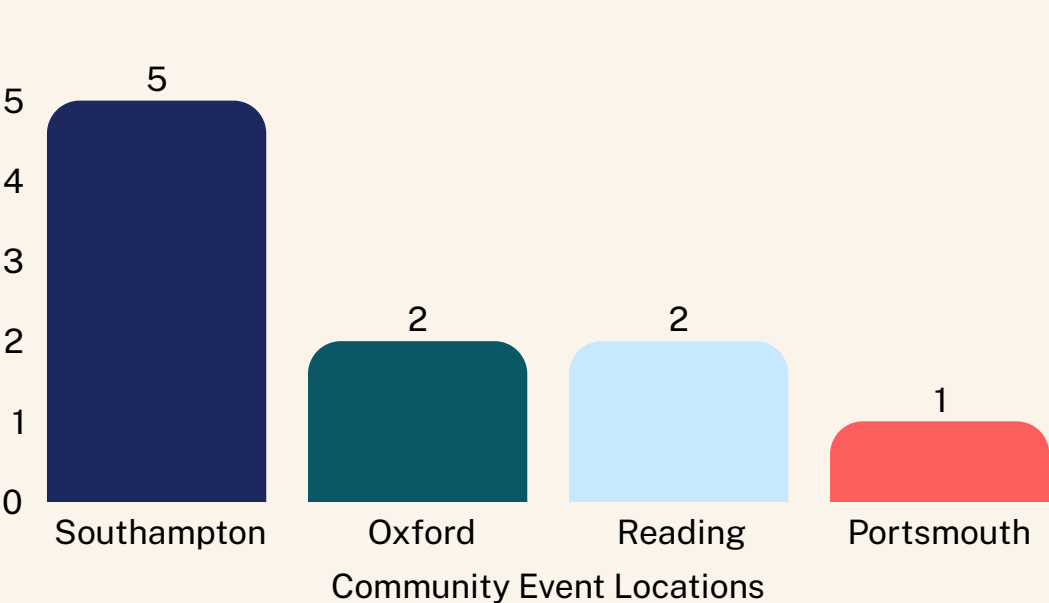
Post-project Evaluation:



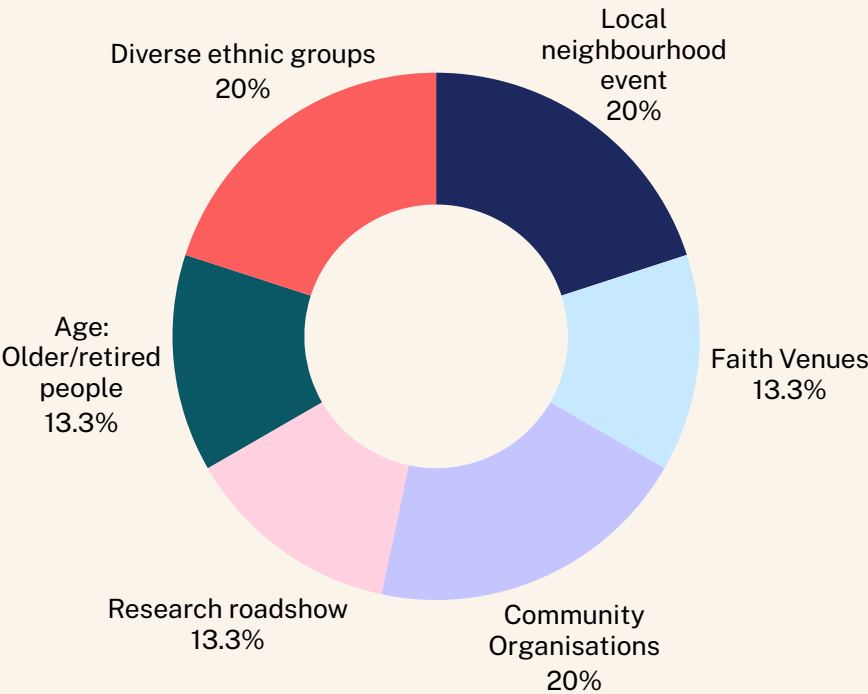
“On the back of this visit, I was invited to three other groups. This shows people appreciate being involved and someone taking the time to listen.”

Research Inclusion Nurse (South Central Ambulance Service (SCAS))

Location and number of events:



The diverse communities engaged:



“The training gave me confidence to talk to different communities, I have been lucky to have experience in attending previous engagement events and I believe the more exposure you have the easier it becomes and having the training is providing those initial tools.”

Research Inclusion Nurse, SCAS

3.2 Refugee Resource

Aim: Refugee Resource is a charity focused on relieving distress, improving wellbeing and facilitating the integration of refugees, asylum seekers and vulnerable migrants in Oxfordshire.

We worked with the Refugee Resource Advisory Group in order to hear the views and experiences of service users in order to improve the services that the charity offers. [Empowering Voices – project poster.pdf](#).

Collaborators: Researchers; Dr Joanna Crocker and Emma Pritchard. Refugee Resource; Susanna Lee, Jacqueline Adusei; member of the Diversity in Research Group, Refugee Resource Director. Facilitators; Cora Reilly-McGeown and Rachel Taylor.

What we discovered:

“The real strength of the Refugee Resource project as a whole was the bottom-up approach, so we could listen to the views of our service users. We now have a member of staff dedicated to recruiting, training and supporting volunteers and that mentoring is to be developed as part of the brief going forwards. Already new 'pairings' are being initiated.”

Susannah Lee, member of the Refugee Resource Charity and Counsellor.

“The Refugee Resource feels like a family!”

Refugee Resource Service User.

Poster opposite created by Emma Pritchard and team shown in photo below at the PCER Conference, June 2026 with Dr Jo Crocker, Rachel Taylor, and Bridget Holligan from the Science Together Team.



Empowering Voices, Building Community

Reflections on a University-NIHR-Charity Research Partnership to Enhance Refugee Support and Feedback

A collaboration between researchers and facilitators from the University of Oxford, the NIHR, and Refugee Resource, a local community organisation through the Science Together Oxford Researchers and Communities (STORC) programme in 2024-2025.

We aimed to develop a **robust system of engagement with and feedback from** clients, enabling Refugee Resource to **review and improve** their service offering.

What we did

Worked with the Refugee Advisory Group (RAG), a group of diverse refugees and vulnerable migrants, to design a feedback process, collect responses and analyse the findings. Over 8 workshops, RAG members identified key groups of clients, developed questions, trained in interview skills, conducted interviews, and analysed the data they had collected. Two evaluation workshops enabled RAG and project team members to reflect on project benefits and challenges.



Project team, Refugee Resource Staff and a Representative of the RAG at the STORC Celebration Event, 2025

Partnership benefits

Refugee Advisory Group members

Developed **key skills** for future work including:

- interviewing;
- active listening;
- managing emotions;
- English language;
- intercultural communication;
- understanding of research.

Built **confidence** in their own skills and abilities

Enjoyed **connecting** with the University

Refugee Resource

Improved **understanding** of client perspectives, leading to recruitment of new staff to build on areas highlighted

Fresh **external energy** to achieve something they couldn't have on their own

Enabled **important reflections** during a time of change

Helped to address **power imbalance** between Refugee Resource staff and clients

A **useful, replicable approach** for gathering client feedback

Increased **credibility** from partnering with University

University Researchers & Facilitators

Developed local knowledge, **relationships** and community **research skills**

Established a **new collaboration** between Refugee Resource and the NIHR Oxford Biomedical research Centre Diversity in Research Group

Felt **nourished and grounded** by RAG meetings

Recommendations for similar partnership projects

- Set clear **timelines and goals** from the outset
- “Structured **slowness**” allows time for relationships and skills to develop
- Undertake **early risk assessment** and mitigation
- Commit time to **regular team meetings** throughout project
- Include at least **two researchers** (with relevant skills) and **facilitators** to guide team
- Provide opportunities to **meet in person**
- Enable people with **lived experience** to actively contribute and develop skills (e.g. provide a familiar, welcoming environment; offer language interpretation, payment for time and formal recognition of skills development; plan for cultural events e.g. Ramadan)
- Evaluate the project **part-way** through as well as at the end
- Enjoy the journey and **celebrate** achievements together

Authors: Emma Pritchard, Joanna Crocker, Susanna Lee, Jacqueline Adusei, Rachel Taylor, Cora Reilly-McGeown, Bridget Holligan
Contact: emma.pritchard@sociology.ox.ac.uk

3.3 Public engagement

Aim: A regular series of public outreach events that drive patient and public engagement in health research, raising awareness and encouraging involvement in research studies.

Collaborators: Communities and researchers across Oxford hospitals and academia.

What we did (2022-2026):

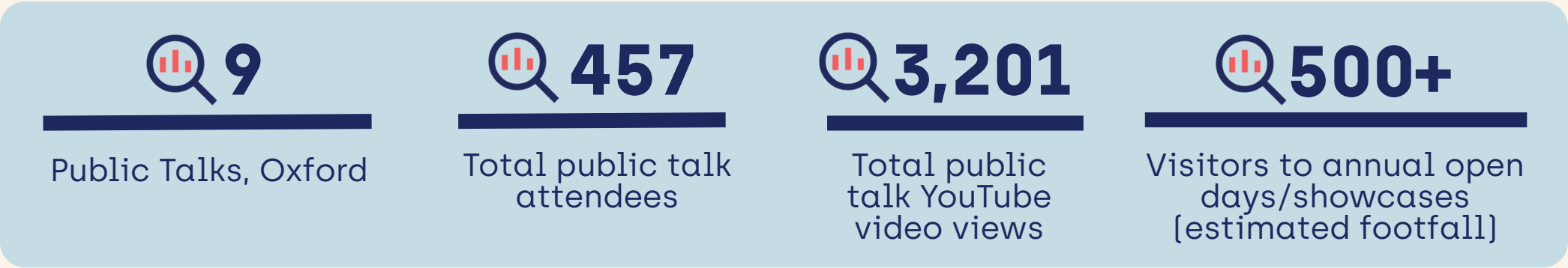
We planned and delivered four Open Days/Health Research Showcases since 2022, with two held at John Radcliffe Hospital and more recently three showcases at Westgate Shopping Centre, Oxford. The annual event is a full-day exhibition in a prime, central location during May half-term which attracts a diverse, family audience. Exhibitor stands demonstrate research from across the BRC Oxford and Oxford Health themes with various activities.

The public talk series invites senior researchers as keynote speakers to share their research and patient experiences of involvement in research with the public via both in-person presentations and webinars. These are recorded and shared widely. [Click here to see videos](#). The Q&A sessions are lively and valuable.

“Our researchers benefited from the opportunity to talk to a large group of people about research. The footfall at the Westgate is very good.”

“We found it useful to have the interactive part of the stand for children to engage but also we took advantage of the opportunity to discuss with the parents/carers and directly support one of our BRC-funded individuals to pose "EDI in clinical trials" questions for their research. This again is another way in which this event not only exhibits what we do with the public but also engages and can help support our research.”

Feedback from researchers exhibiting at the showcase.



4.0 Supporting Researchers



4.1 Training for researchers: Introduction to PPI

Context: The Introduction to PPI course has been developed to train and support researchers to undertake PPI with confidence and to feel supported by a wider team of experts.

What we deliver:

A ninety-minute online training course is delivered with four courses, six times a year. These sessions are available to all.

We utilise a film made by BRC Oxford’s Diversity in Research Group and NIHR-funded researchers during the session.

Evaluation findings:

Attendees reported increased PPIEP knowledge, confidence and take home learning as a result of attending the training.



- We asked five questions at the end of the sessions:
- Head - what did you learn?
 - Heart - what did you love?
 - Hands - what will you do?
 - Bin - what could you do without?
 - Next steps for PPI training – what should we do next for training?

“ I feel more confident for chairing PPI meetings. ”

“ The videos were really helpful to hear different voices and perspectives. ”

“ I understand now that they are not 'hard to reach' groups just groups we haven't been doing well at reaching. ”

“ The evaluation session has encouraged me to think about how to engage public/patients and how much this is needed so that changes to healthcare holds them at the centre of that. ”

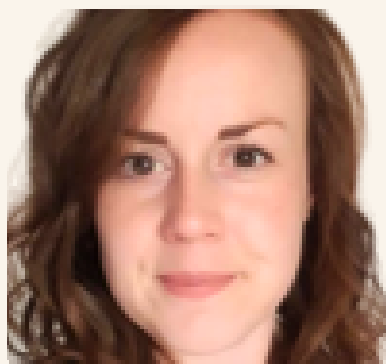
“ I feel more knowledgeable and confident ”

Feedback from
evaluation sessions,
2023 -25.

Research Inclusion Training for researchers

Context: A survey for researchers, co-designed with the Diversity in Research Group, revealed that researchers had low awareness of ethnicity inclusion resources. As a result, NIHR BRC/CRF: Oxford led a joint BRC Research Inclusion training programme involving expert speakers and evolved this over two years.

Collaborators: Diversity in Research Group and NIHR Biomedical Research Centres: Barts, Birmingham, Cambridge, Moorfields, Oxford, Oxford Health and the following specialist subject experts.



Cherish Boxall, founder of Engage Intelligently, and recipient of two consecutive NIHR Fellowships, brings a behavioural-science lens to over 15 years of experience.



Dr Heidi Green is a Health Equity and Patient Involvement Specialist and Creative Qualitative Researcher who co-developed the NIHR INCLUDE Socio-economic disadvantage framework



Professor Shaun Trewick is active in the field of efficient trial design, complex interventions and recruitment. He co-developed the NIHR INCLUDE Ethnicity Framework.

March 2024:

Hosted in-person Ethnicity Inclusion Workshop- 1 session.
Collaborators: BRC Oxford and Oxford Health.

2024 - 2025:

Ethnicity Inclusion training – 3 sessions.
Collaborators: Diversity in Research (DiR) Group (PPIE group), BRC Oxford Health and BRC Cambridge.

2025 - 2026:

Training collaboration – 9 sessions.
Collaborators: Six NIHR Biomedical Research Centres: Barts, Birmingham, Cambridge, Moorfields, Oxford Health and Oxford.

*Data from Spring 2026 sessions.

Post-training evaluation 2025-2026:

Webinar: Behavioural Approaches to Inclusion

Registered | Attended | Increase in Confidence Post-Training

470 349

After 2 sessions*

44%

Enhancing Communication Approaches with the public with Behavioural Science.

Webinar: Ethnicity Inclusion NIHR INCLUDE Framework

Registered | Attended | Increase in Confidence Post-Training

437 304

After 2 sessions*

54%

Using the framework after training.

Webinar: NIHR Socio-economic Disadvantage Inclusion Framework

Registered | Attended | Increase in Confidence Post-Training

480 324

After 2 sessions*

55%

Applying the framework after training.

4.2 Training for registered Healthcare Professionals (rHCPs)

Context: The BRC Oxford PPIEP team support rHCPs to understand and implement PPIEP in their research and quality improvement (QI) projects.

We deliver small group training to rHCPs who have received funding for research or QI either from the BRC Oxford Intern programme or the Chief Nursing Officer (CNO) Fellowship programme.

The BRC Oxford internships are research ‘tasters’ and aimed at people with no or limited previous experience of research. The CNO fellows undertake Service Improvement/Quality Improvement projects which addresses key priorities for the Trust.

What we deliver:

A ninety minute training session covers an introduction to PPIEP, offering knowledge and experience around identifying and working with public partners and stakeholder groups, particularly those from under-served communities.

Each session allows time for individual support to focus on the needs of the particular projects the rHCPs are working on. Sixty-minute follow-up sessions provide more in-depth one-to-one support.



“The programme has been consistently well received and made a meaningful contribution to building understanding, confidence and capability in PPI. In particular, the training raised awareness of why PPI is such a critical component of high-quality research, throughout the research lifecycle—not as a tokenistic exercise, but as a way to improve relevance, quality, ethics and impact. The emphasis on real-world examples and practical application has helped participants to see how PPI can shape research questions, study design, recruitment strategies, interpretation of findings and dissemination. This has been a valuable investment that is clearly translating into better-informed, more inclusive research practice.”

Dr Clair Merriman, Divisional Lead for NMAHPP Research and Innovation, Oxford University Hospitals Foundation Trust and Oxford Brookes University.

4.3 Bespoke support for researchers

Context: The PPIEP team supports individual researchers to deliver meaningful PPIEP that adds value to research.

What we deliver:

The team provide one-to-one sessions with researchers for a tailored PPIEP approach. We particularly support early career researchers who may not be confident on how best to approach involving members of the public.

Public partners and the Oxford PPIEP staff group have developed templates and guidance for researchers undertaking PPIEP which are available to, and accessed by researchers in Oxford and across the UK.

Researchers can post their involvement opportunities on the BRC Oxford involvement listings page allowing them to link with the public members who have joined the mailing list and who are able to help with research projects

**Involvement Opportunities
[2023- 2026]:**

**130**

Researchers advertising opportunities for PPI

Quote: Dr Yuhan Zhang (second from right), Advanced Nurse Practitioner, Image: Dr Zhang and colleagues.

“ The PPIE team added significant value to the Frailty and Ambulatory Outreach projects by supporting inclusive engagement, helping us hear voices that might otherwise have been missed, and keeping the project grounded in what matters to patients and families. Rachel and Mili’s involvement improved the relevance, acceptability and emotional safety of the project outputs and made the work more meaningful for both staff and those receiving care. ”



4.4 Researcher Recommendations

Context: In 2025, a group of patient and public involvement contributors developed some key recommendations for researchers when engaging with under-served communities, including ensuring that the right people are involved, building relationships and being mindful of practicalities, such as payment and accessible venues.

Researchers are encouraged to read these recommendations: [Online PDF: Researcher Recommendations](#)



Before your PPI activity

1

Seek PPI as early as possible, ideally when research ideas and questions are beginning to form. See [guidance for recruiting patients and the public](#) and examples from [our review about involving under-served communities](#).

2

Plan PPI across multiple stages: Consider when and how to involve PPI contributors throughout the [research cycle](#). Plan sufficient time and resources to support this – see further guidance on [costing and funding PPI](#) and [paying PPI contributors](#).

3

Clarify purpose and expectations: Explain clearly to PPI contributors (i) why you are seeking their views; (ii) which perspectives you especially need; (iii) whether their involvement is one-off or there are opportunities for further involvement – if the latter, provide a [role description](#).

During your PPI activity

1

Clarify scope of input requested: Be clear with PPI contributors about which aspects of your research can and cannot be changed.

2

Provide clear, accessible information about your research.

- If you are planning to give a talk, use the [OxBRc guidance for PPI talks](#).
- Follow guidance on [writing in Plain English](#).

3

Ask specific, open questions to help PPI contributors give useful advice. You could consider using [creative methods](#) if appropriate.

4

Request personal information transparently: If you need specific information about PPI contributors’ characteristics or experience, don’t be afraid to ask, but explain clearly why you need each piece of information and what you will do with it (including how you will store and use it).

- Offer “other” and “prefer not to say” options.
- Avoid making assumptions about PPI contributors’ characteristics or experience; this information should come directly from them.

5

Record contributions visibly and inclusively: For example, a member of your team could be responsible for noting down all PPI contributors’ suggestions on a flipchart or shared screen; this could then be collectively reviewed at the end of the meeting and a final version distributed to contributors.

- Be careful that suggestions are not immediately dismissed and therefore not recorded. It may help if the notetaker is a PPI professional or someone else who is not a researcher.
- Invite PPI contributors to correct any misinterpretations.

After your PPI activity

1

Review and respond to suggestions: Consider each suggestion offered by PPI contributors and why you will or won’t act on it.

If a suggestion seems irrelevant, before dismissing it ask yourself *why* it is irrelevant, and why you might not have got the advice you wanted. Consider whether what you *need* to hear might not always be what you *want* to hear (and vice versa).

If a suggestion can’t or won’t be implemented within your current project, consider how to respond sensitively and whether you have learned anything you might take forward into future research. Is there anything that could be highlighted in the project report/publication for consideration in future research?

2

Reflect on feedback and learning: What have you learned from the post-activity questionnaire (if you used one) and your own experiences of the PPI activity as researchers? What might you do differently in future?

If your PPI activity will be repeated with the same contributors (e.g. a recurring meeting), share feedback from the previous activity at the beginning of the next activity and show how this has been considered or led to improvements.

3

Provide feedback to PPI contributors regarding the difference they have made to you, your project and/or your future research, ideally in conversation (rather than just email). This could be in a “you said, we did” format. Include your own learning as well as any impacts on your research. See [guidance on feeding back to PPI contributors](#).

4

Continue communicating with PPI contributors throughout the research, including sharing updates on grant applications, research findings and outputs.

NIHR BRC/CRF: Oxford PPIEP Impact Report, 2022-2026

5.0 Evidencing the Impact



5.1 Impact of diverse public involvement in health research

A BRC Oxford participatory research project with members of the Diversity in Research Group explored how to maximise the benefits of diverse public involvement. This involved 42 interviews with public partners, PPIEP staff and researchers.

The project found that the diverse group had a positive impact on: Research, Researchers and Group members.

A poster (opposite) was presented at the [ENGAGE Summit](#) and [Oxford University's PCER Conference](#).

Read the poster online here: [Impact of diverse and inclusive public involvement in health research](#).

Members of the Diversity in Research Group co-produced a literature review exploring outreach with under-served communities. [Click to read the resulting paper which was chosen by Springer Nature as its article of the month](#).



Photo: Dr Jo Crocker, Magdalen Wind-Mozley, Corina Cheeks and Richard Mandunya, with Rachel Taylor.



Impact of diverse and inclusive public involvement in health research

The **Diversity in Research Group** was set up by the NIHR Biomedical Research Centres: Oxford and Oxford Health to improve how members of the public are involved in health research, especially people from communities who aren't usually involved. When people are involved, it means they help researchers decide what research is done and how it is done.



Understanding what difference the group makes

With group members' guidance at every stage, we studied the group's activities with researchers to understand the difference they make and how this could be improved. Here are some of the positive differences the group made...



...to Research

- Improved communication about the research to diverse communities
- Helped to win funding for the research to happen
- Changed what the research was testing
- Expanded who was involved in the research and how they were involved



... to Researchers

- Learned about what matters to diverse communities
- Reflected on how they involve people in research
- Gained confidence to connect with different groups of people
- Gained confidence in their research ideas



... to Group members

- Learned about medicine, health and research
- Developed new skills in communication and research
- Built friendships and support for each other
- Gained confidence



How to improve the group's impact

Our study also looked at how the Diversity in Research Group could make even more positive differences to research. This led us to create new [recommendations for researchers planning patient and public involvement \(PPI\) activities](#).

Authors: Joanna Crocker, Corina Cheeks, Richard Mandunya, Magdalen Wind-Mozley, Manoj Mistry, Hameed Khan, Noémi Roy, Rachel Taylor.
With many thanks to the Diversity in Research Group and all who took part in the study.
Contact: joanna.crocker@phc.ox.ac.uk Click to read more about the [Diversity in Research Group](#).

5.2 Co-producing research with communities and policymakers

BRC Oxford works with the Oxfordshire County Council to address local health inequalities.

The BRC Oxford Senior PPI Researcher undertook a Fellowship in 2024, funded by the Oxford Policy Engagement Network. They worked with community and policy partners on a rapid evidence synthesis and workshop to co-develop recommendations for the Oxfordshire Community Research Network's (OCRN) development.

The findings directly informed the OCRN strategy for the next five years. For example, the top recommendation related to the provision of a local incubator fund for community-led research. This has now been implemented and will fund several local research projects. The review findings will be published in an academic health journal.

As Chief Scientific Advisor to the Oxfordshire Local Policy Lab the BRC Oxford Senior PPI Researcher leads the co-development of a research agenda with local communities, policymakers and academics to **“Address inequalities and ensure a healthy standard of living for all”**.

Image credit: stock photo.



5.3 Measuring and reporting

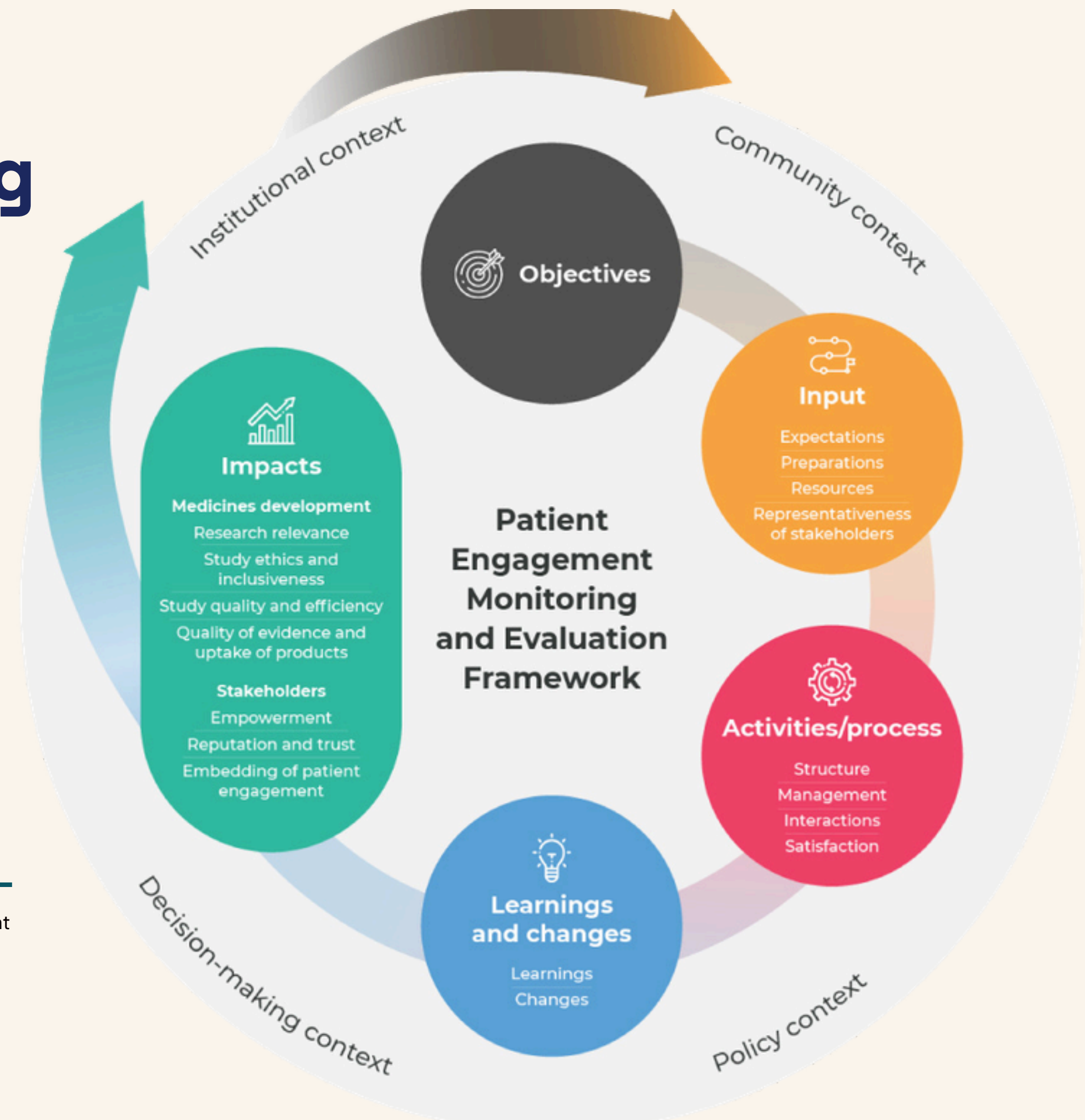
BRC Oxford provides advice and training to researchers and PPIEP professionals locally and nationally on PPIEP evaluation and impact assessment. This includes supporting researchers to understand and apply available tools:

- Public Involvement in Research Impact Toolkit (PIRIT)
- Cube Evaluation Framework
- Public and Patient Engagement Evaluation Tool (PPEET)
- PARADIGM Patient Engagement Monitoring & Evaluation Framework (opposite)
- PPI Impact Log

We provide guidance to local and national groups. For example, presenting evaluation tools to the national NIHR BRC PPIEP Leads Group. Our aim is to develop and test a measure of meaningful PPI called the Patient-Centered Outcomes Research Engagement Measure (PCOR-EM), led by the University of Massachusetts Boston.

We also collaborate with international partners to develop a PPI impact reporting guideline, led by the University of Sydney.

Image: The PARADIGM Patient Engagement Monitoring and Evaluation Framework , created by authors from the VU-Athena Institute with Laiba Husain and Teresa Finlay from the University of Oxford.



How to reach us:

NIHR BRC: Oxford Website: <https://oxfordbrc.nihr.ac.uk/>

NIHR CRF: Oxford Website: <https://oxfordbrc.nihr.ac.uk/research-themes/nihr-oxford-clinical-research-facility/>

PPIEP team: <https://oxfordbrc.nihr.ac.uk/ppi/>

Email our PPIEP Lead: Rachel.Taylor@ouh.nhs.uk

