

Introduction to the NIHR Imperial Patient Experience Research Centre (PERC) and Public Involvement in Research



Health Professionals Academic Group
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Patient Experience Research Centre

- Established in 2011 by Helen Ward (Clinical Professor of Public Health) and Sophie Day (Professor of Anthropology).
- **Core facility** of the NIHR Imperial Biomedical Research Centre
- Sits within the **School of Public Health** (Department of Epidemiology and Biostatistics)
- Promote, advise & undertake **participatory approaches** to healthcare & biomedical research
- Utilise **quantitative & qualitative methods**
- Interpret findings into action/policy recommendations
- Provide **public involvement support**, training & advice to BRC linked researchers
- Staff fellowship programme (2 x 6 months)


NIHR | Imperial Biomedical Research Centre

Patient Experience Research Centre


The Patient Experience Research Centre (PERC) is a core facility of the NIHR Imperial BRC that aims to improve the quality of healthcare services and impact of translational research through public involvement and engagement.




Public Involvement Training
In collaboration with the Imperial Clinical Trials Unit (ICTU), PERC offers free training sessions for researchers and members of the public to learn about meaningful involvement in health research.




Health Research Matters
A monthly seminar series showcasing research relevant to patient experience and health. The seminars are open to all: researchers, healthcare practitioners and members of the public.




PERC Blog
Researchers write blogs and case studies, which share the latest public involvement examples, news and best practice.



Online Resource Hub
Guidance and support on public involvement compiled specifically for use by Imperial researchers.




The People's Research Cafe
Members of the public contribute to research projects in an informal pop-up 'café' space usually located in the community.



Research Expertise
PERC's work is primarily focused around developing new methods for gathering and analysing patient experience, which is recognised as a key element of the quality of healthcare, along with patient safety and clinical improvements.



VOICE at Imperial
A digital platform that connects researchers with members of the public willing to share their ideas and lived experience to improve research and innovation.
www.voice-global.org



Young Persons' Network
A network of 17 to 25 year-olds interested in designing and shaping different kinds of research taking place across Imperial.

PERC activities

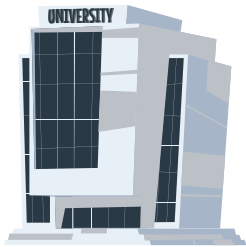
Find out more at www.imperial.ac.uk/patient-experience-research-centre

Get in touch
For public involvement enquiries: +44 (0) 207 594 3822 ppi@imperial.ac.uk
For research enquiries: +44 (0) 207 594 3464 patientexperience@imperial.ac.uk
For VOICE at Imperial enquiries: +44 (0) 207 594 3417 voice@imperial.ac.uk

[@Imperial_PERC](https://twitter.com/Imperial_PERC) [@ResearchCafes](https://twitter.com/ResearchCafes) [@VOICE_Global](https://twitter.com/VOICE_Global)

What is the Imperial Biomedical Research Centre (BRC)?

- A partnership between academics (Imperial College) and clinicians (Imperial College Healthcare NHS Trust)
- Funded for 5 years by the National Institute for Health and Social Care Research (NIHR) (Dec 2022 – Nov 2027).



Imperial College, London
[University]



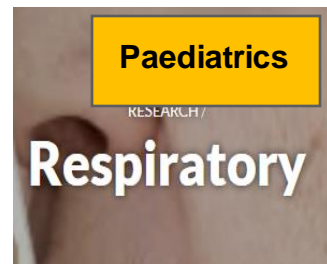
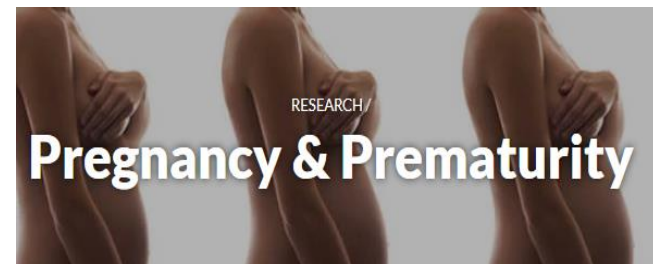
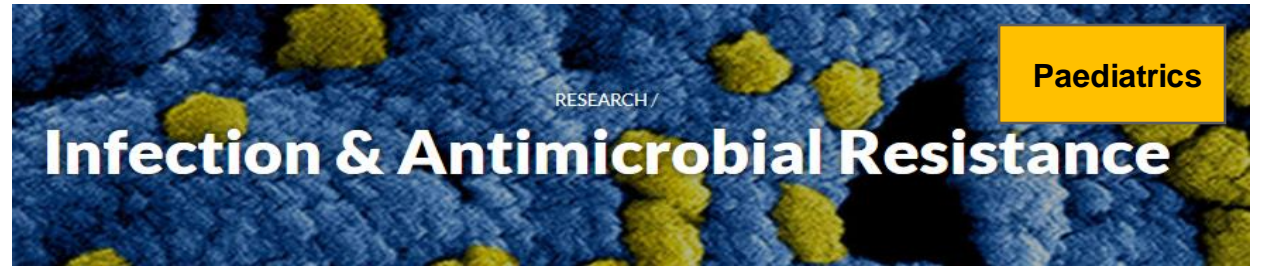
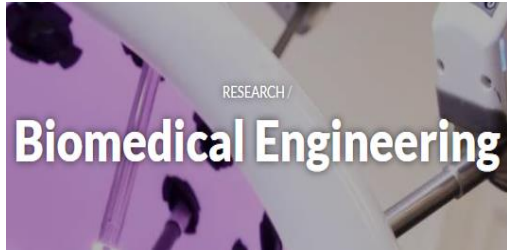
**Imperial College Healthcare
NHS Trust**

- Queen Charlotte's & Chelsea Hospital
 - Hammersmith Hospital
 - Charing Cross Hospital
 - St Mary's Hospital
 - Western Eye Hospitals

We are 1 of 19 BRC's across England. Our BRC covers the below boroughs of North-West London



15 BRC Research Themes (2022 to 2027)



Who are the “public” in “public involvement”?

“**Public**” includes patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they’re current patients or not.

However, whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

The “public” are one set of stakeholders who are important to research *but all stakeholders should be involved as far as possible from beginning to end.*



National Institute of Health & Care Research (NIHR) PPIEP Definitions



Co-production

Researchers, healthcare professionals & the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

Further information on co-production:

- [NIHR guidance](#)
- [UCL Centre for Co-production](#)
- [Co-Production Collective](#)

Public involvement

Research is carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. An active partnership between patients, carers and members of the public with researchers that influences and shapes research e.g., patients identifying a research question.

Public engagement

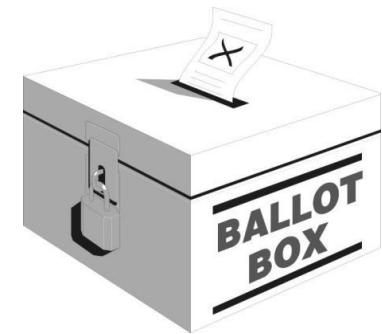
Providing & disseminating information & knowledge about research to the public; discussing & consulting with the public e.g., Science Café or giving a talk to a charity

Public participation

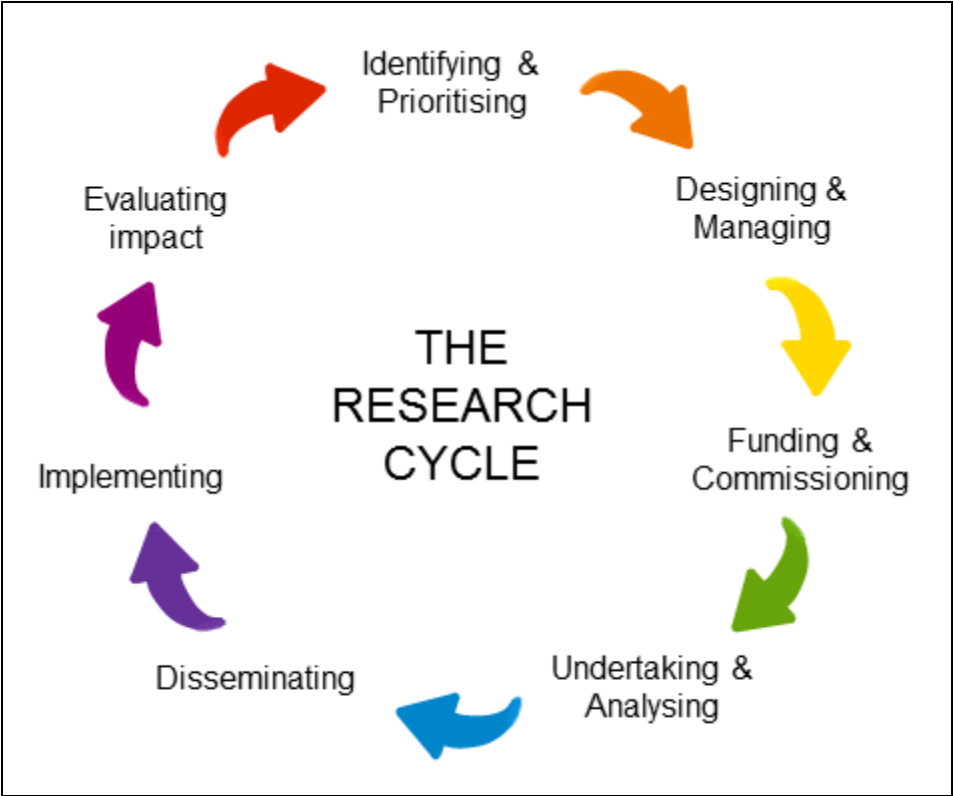
Members of the public/patients as participants of research studies e.g., clinical trials, qualitative studies, (interviews, surveys), observational studies, biobanks.

Why do Public Involvement in research?

- Ethical right
- Democratic right
 - Accountability
 - Transparency
 - Build trust
- Utilitarian argument
 - Better designed
 - Ensures fit for purpose
- Avoids waste research
- Ensures relevant to population
- Addresses unmet need
- Increases impact
- Mandated by funders
- Builds relationships
- Fun!

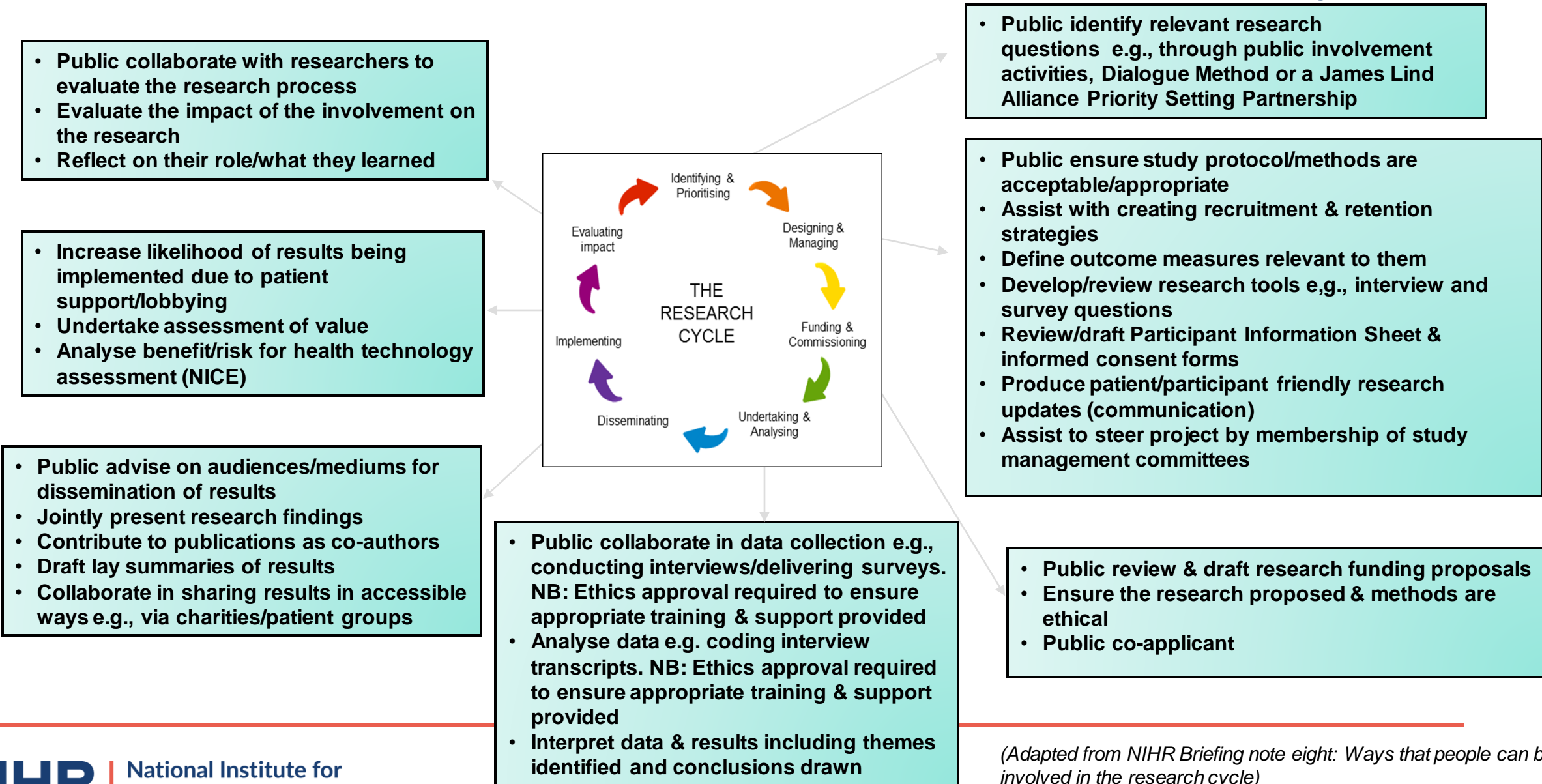


Public Involvement around the Research Cycle



(adapted from NIHR)

Examples of Public Involvement around the Research Cycle



(Adapted from NIHR Briefing note eight: Ways that people can be involved in the research cycle)

How does PERC support PPIEP?



Online Resource Hub

Guidance and support on public involvement for Imperial BRC linked researchers, but accessible to all.



Public Involvement Training

Free online course - introduction to public involvement in research (for researchers & some public contributors). Co-delivery of public involvement training to students.



PPIEP Support

Implement & co-deliver the [Imperial BRC PPIEP Strategy](#), provide PPIEP advice to BRC linked researchers



Public Networks

Networks of public citizens, including a Young Person's Advisory Network (17-25 year-olds), PERC mailing list & Community Partner network



People's Research Cafes

Researchers' take projects into the community to discuss these in informal 'pop-up' cafes in community venues

Imperial BRC PPIEP Strategy (2022 – 2027)



- 10 aims
- Action Plan which each theme should comply with

KEY INDIVIDUALS



Professor Helen Ward

THEME LEAD, SGE, PROFESSOR OF PUBLIC HEALTH AND DIRECTOR, PERC



Prof Mary Wells

PROFESSOR AND LEAD FOR NURSING AND MIDWIFERY - THEME COMMITTEE MEMBER



Professor Sophie Day

VISITING PROFESSOR OF ANTHROPOLOGY

Public Involvement, Engagement and Participation in Research Strategy

2022 - 2027 Summary

OUR VISION

The Imperial Biomedical Research Centre (BRC)'s vision is to achieve inclusive and accountable public involvement and engagement that is embedded across the BRC, leading to improvements in health and wellbeing most relevant to the needs of our Northwest London population.

RESEARCH THEMES

BIOMEDICAL ENGINEERING

BRAIN SCIENCES

CARDIOVASCULAR

DIGESTIVE DISEASES

DIGITAL HEALTH

IMMUNOLOGY

INFECTION & ANTIMICROBIAL RESISTANCE

METABOLIC & ENDOCRINE

MOLECULAR PHENOTYPING

Imperial BRC Community Partner Framework

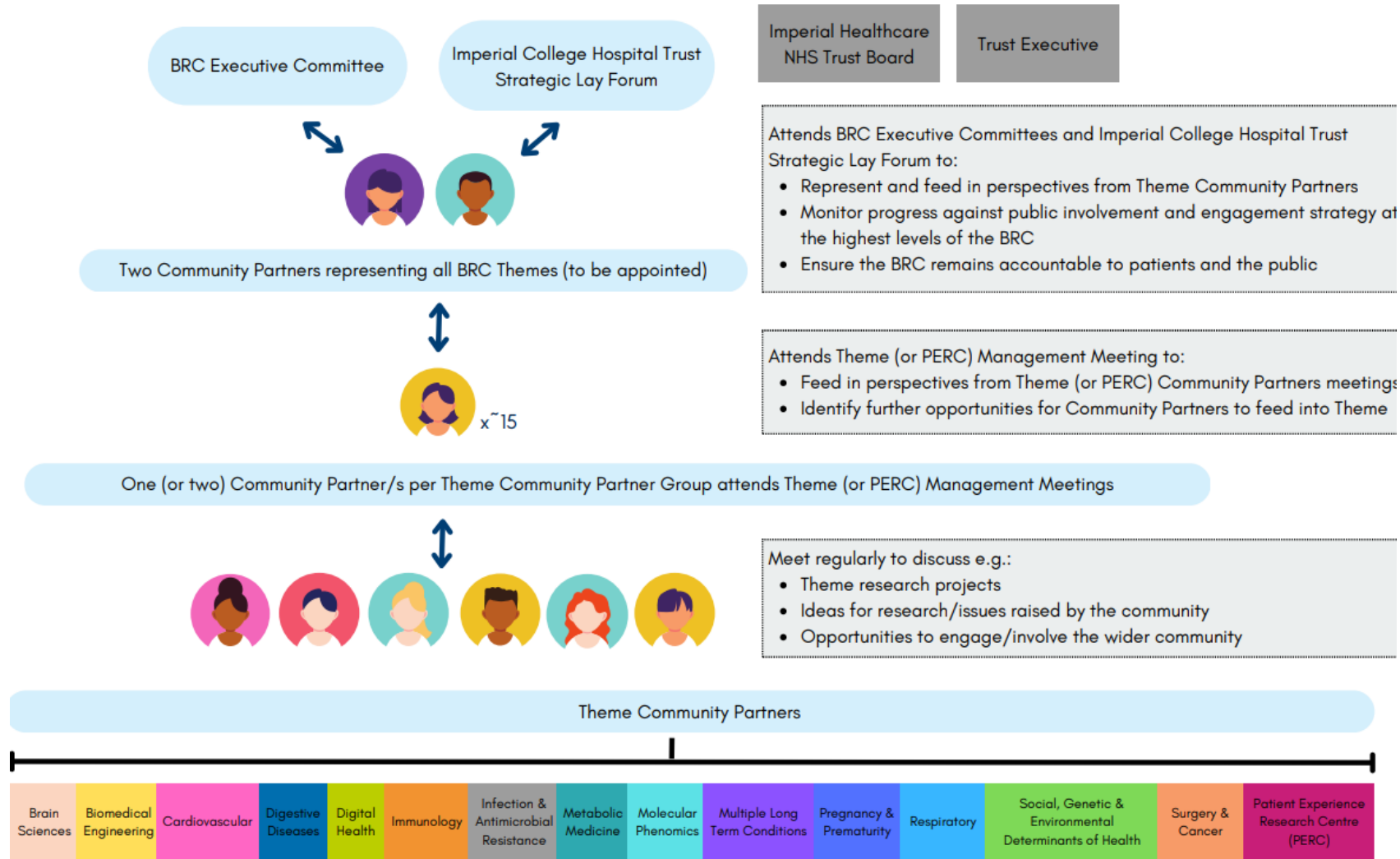


Diagram 2. Community Partner Framework showing how Community partners will feed into the BRC across levels

People's Research Cafes

- Aim to give the public a flavour of public involvement by contributing to research projects
- Allows for fresh input in a welcoming environment and in a novel and fun way
- Blogs from projects hosted at People's Research Cafe at Great Exhibition Road Festival 2022



Join us for a **free cup of tea or coffee and cake** and have a chat with health researchers!

Email ppi@imperial.ac.uk to find out more



Drop by!

Fri 6th
December

13:00 - 15:00



Charecroft Estate Community Hall,
Rockley Rd, Hammersmith,
London W12 8PQ



Imperial College
London

Insight reports for public involvement and engagement



Building our Digital Health Programme in North West London

Read the summary report from our Zoom call on 07 July 2021 with members of the public about their views on how digital health could improve clinical care, the health of the community and research.

[Learn more](#)



Real World Evidence Studies to Improve Health and Care

Read the summary report from our Zoom call on 21 July 2021 with members of the public about their views on using routinely collected health data (i.e. real world evidence) for research.

[Learn more](#)



Using Artificial Intelligence to Improve Health and Care

Read the summary report from our Zoom call on 4 August 2021 with members of the public about their views on the use of artificial intelligence to improve clinical care.

[Learn more](#)



Use of the Wynn Database for Metabolic Research

Read the summary report from our Zoom call on 29 July 2021 with members of the public with lived experience of metabolic disease (e.g. diabetes) about their views on the use of historic database.

[Learn more](#)



Social, Genetic and Environmental Determinants of Health

Read the summary report from our Zoom call on 1 Sept 2021 with members of the public about their views on research relating to social, genetic and environmental determinants of health.

[Learn more](#)



Weight and Fertility

Read the summary report from our Zoom call on 2 Sept 2021 with members of the public about their views on weight and fertility research and service provision.

[Learn more](#)

Science of Digestion Insight Report

Summary report of the Science of Digestion event co-led by Guts UK on 26th April 2022 at Ealing Town Hall. The report includes an overview of the event and the insights raised by the public who attended.

[Download the report](#)

Inflammatory Bowel Disease Public Involvement Insight Report

Read the summary report from our Zoom call on 12th July 2022 with people with lived experience of Inflammatory Bowel Disease (IBD). The report includes their views on a proposed research project exploring a more personalised approach to diagnosis and treatment of IBD.

[Download the report](#)

Ovarian Cancer and Health Data Public Involvement Insight Report

Read the summary report from our Zoom call on 27th April 2022 with people with lived experience of ovarian cancer (as a patient or carer) about their views on a new research project exploring the use of routinely collected data to improve outcomes for people with ovarian cancer.

[Download the report](#)

Cardiovascular Research Public Involvement Insight Report

Read the summary report from our Zoom call on a proposed programme of cardiovascular research held on 7th August 2023 with a selection of Imperial Biomedical Research Centre (BRC) Community Partners linked to related Imperial BRC research themes.

The report includes views from the Community Partners on the programme's four proposed areas of cardiovascular research.

[Download the report](#)

Underrepresentation in research

Those who take part in research studies (or help to shape them) are often not representative of the diversity in society or the community most at risk of being affected by a health condition.

Many factors contribute to this e.g. historical unethical research studies, mistrust of research and research institutions, the need for research to be more: inclusive; accessible; relevant to under-represented communities

We:

- work to build trust with underrepresented communities by:
 - creating **reciprocal relationships** e.g., find speakers for health literacy sessions or community events, being present at community events
 - connect researchers with communities to demystify research/ers, Imperial & build trust with a view to involvement and participation (e.g. ICS REN Roadshows)



A few practicalities



- Ethics committee approval only needed for public involvement when members of the public are assisting in **undertaking research and analysing the data**
- Recognise the value of people's lived experience and show appreciation. Give people feedback about their input and its impact in order to keep them involved and to be able to report it.
- NIHR Payment policy for public involvement
- Keep names and contact details of members of the public secure

Imperial Patient Experience Research Centre (PERC) PPIE Resources

- [Website](#)
- [Imperial BRC PPIEP Strategy Key Actions](#)
- [Rough Guide to Public Involvement](#)
- [Public involvement for grant applications](#)
- [Public Involvement Resource Hub](#) – guidance, case studies, template documents
- [Free Public Involvement in Research Online Training Course](#) (for members of the public and researchers – free Certificate of Completion for Imperial researchers & NHS staff)
- [Free Participatory Research Training Courses](#) – (for members of the public and researchers – free Certificate of Completion for Imperial researchers & NHS staff)
- [Blog](#) – with examples of public involvement in research
- [Twitter/X @Imperial PERC](#)
- [Instagram: imperial_perc](#)
- [Email: publicinvolvement@imperial.ac.uk](mailto:publicinvolvement@imperial.ac.uk)

Public involvement networks:

- [Community Partner network in NWL across all BRC Themes](#): a network of 75 people with wider community connections with whom we share public involvement/engagement opportunities
- [Young People's Advisory Network \(17 to 25 years\)](#) – a network of young people to whom we send public involvement in research opportunities through email or regular newsletters.
- [PERC mailing list](#) – PERC mailing list (national) for members of the public to which we send a newsletter with public involvement/engagement opportunities every 3 months.
- [People in Research](#) – National Institute for Health and Care Research (NIHR) website to promote public involvement opportunities.

Diversifying Research Resources (1)

NIHR INCLUDE Project:

- Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project - examples of good practice and resources to guide teams seeking to engage with, and improve inclusion of, under-served groups in health research.
- INCLUDE Ethnicity Framework - aims to help research trial teams think carefully about which ethnic groups should be included in their trial for its results to be widely applicable, and what challenges there may be to making this possible.
- INCLUDE webpage – updated with relevant training and resources
- "Ensuring that COVID-19 research is inclusive: guidance from the NIHR INCLUDE project" (<https://bmjopen.bmj.com/content/10/11/e043634>)

The Centre for Ethnic Health Research:

- Ensuring ethnic diversity in research - advice for researchers
- Increasing participation of Black Asian and Minority Ethnic (BAME) groups in health and social care research: a toolkit to capture best practice and provide a framework

Diversifying Research Resources (2)

Diversity in public involvement:

- [NIHR Being Inclusive in Public Involvement in Health Research](#)
- [NIHR Reaching Out: A practical guide to being inclusive in public involvement in health research – Lessons learnt from the Reaching Out programme](#)
- [NIHR: A guide to creating inclusive content and language](#)

Training:

- [NIHR INCLUDE online course](#) - accessible online through NIHR Learn. For new users, you will be prompted to register at the login page. Upon completion of the registration form, you will then have access to the course

Other resources:

- Pan D, Sze S, Minhas JS, et al. The impact of ethnicity on clinical outcomes in COVID19: a systematic review. [EClinicalMedicine 2020;](#)
- Treweek S, Forouhi NG, Narayan KMV, Khunti K. [COVID-19 and ethnicity: who will research results apply to? Lancet.2020;395\(10242\):1955-1957.](#)
- ["Developing a roadmap to improve trial delivery for under-served groups: results from a UK multi-stakeholder process"](#)
- [Marmot Review report – 'Fair Society, Healthy Lives | Local Government Association](#)
- [Mind-the-Gap-A-handbook-of-clinical-signs-in-Black-and-Brown-skin.-first-edition-2020.pdf \(litfl.com\)](#)
- [Racial Bias in Pulse Oximetry Measurement | NEJM](#)
- [Co-POWeR: Consortium on Practices of Well-being and Resilience in BAME Families and Communities](#)

“People focused research in the NHS simply cannot be delivered without the involvement of patients and the public. No matter how complicated the research or how brilliant the researcher, patients and the public always offer unique, invaluable insight.”

*Professor Dame Sally Davies, Former Chief Medical Officer and Chief Scientific Advisor,
Department of Health.*

