



Imperial College
Academic Health
Science Centre
Improving Patient Care



Involving and engaging the public

Inspiring good practice in
biomedical research



NIHR Imperial Biomedical Research Centre
Translating research into patient benefits

NHS
*National Institute for
Health Research*

About us

The **Imperial College Academic Health Science Centre (AHSC)**, a partnership between Imperial College London and Imperial College Healthcare NHS Trust, utilises excellence in research and education to transform health outcomes. The **NIHR Imperial Biomedical Research Centre (BRC)** is the engine of the AHSC. We, at the BRC, undertake translational research, which means taking the findings from basic research and quickly turning them into healthcare and medical practice improvements. Our work leads to benefits in health and wellbeing of patients.

The **Imperial Patient Experience Research Centre (PERC)** is a multidisciplinary research unit aiming to understand how patients and the public experience clinical care and research. PERC is the mechanism which ensures that patient involvement and engagement are embedded throughout the work of the BRC; our research programme includes feasibility and impact studies of involvement and engagement in research. Our research directly benefits patients and the local population.

What we do

At the NIHR Imperial BRC and PERC, we work closely with patients and the public to ensure that their wealth of experience and perspectives shape the design and delivery of biomedical research.

This publication outlines our patient and public involvement and public engagement strategy and showcases examples of involvement and engagement from research groups across the BRC and partners in order to inspire good practice.

What are patient and public involvement and public engagement?

Patient and public involvement (PPI) is where patients, carers and members of the public are actively involved in research, for example through:

- the development and prioritisation of research questions
- the design of questionnaires, information sheets and advising scientists on processes
- joining ethical and governance committees or patient groups
- data collection and analysis
- dissemination of findings.

Public engagement (PE) can be achieved by informing the public about our research, for example through:

- outreach activities, including festivals, art installations, public lectures and forums
- production of videos, development of games and work with the media
- outreach to schools and communities
- open labs coffee mornings and informal tours of research centres
- social media and digital outreach, including websites, blogs, Twitter and videos.

Being involved or engaged is different from research 'participation', which is where people take part in a research study.



Professor Jonathan Weber
Director, NIHR Imperial BRC



Professor Helen Ward
Director, Imperial PERC



Our strategy



Building capacity

- We have recruited dedicated staff and funds for PPI within PERC.
- We are developing the organisational structure for PPI and PE support across Imperial (for example, we have set up a NIHR Imperial BRC Patient and Public Panel).
- We will continue to produce guidance and policies (i.e. rewards, recognition and good practice guidelines).
- We offer small grants for PPI and PE activities.

Monitoring and learning

- We offer training and resources for researchers, patients and public representatives.
- We track involvement and engagement activities to enable sharing good practice, evaluation and review.
- We will adopt standards or tools for evaluation and review.



Collaborating

- We have set up strong internal and local external networks of involvement and engagement leads and advocates (i.e. Imperial BRC PPI/PE Virtual Network, Imperial and Partners PPI Research Forum).
- We will continue working with these and other national networks to encourage shared structures and approaches to avoid duplication.

Assessing the impact of involvement and engagement

- We are using demonstration projects to assess the impact of PPI and PE.
- We will work with our partners to develop research to deepen our understanding of the role of such activities in translational research.



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Building capacity

We are committed to building PPI and PE capacity and expertise across Imperial, by developing organisational structures, introducing guidance, and supporting individual research themes and groups. Examples where effective involvement or engagement practices have ensured the growth of capacity, are highlighted below.



INVOLVEMENT:

Migrant health

Research on migrant health requires sensitivity and understanding to ensure that it is appropriate and acceptable. One research project led by Dr Sally Hargreaves and Farah Seedat, Infectious Diseases, explored the views of new migrants on screening. The team worked closely with community organisations and carried out a public consultation in a diverse local area to help refine research questions and identify appropriate groups to invite for further involvement and collaboration. Through this initial work, the team were able to recruit a migrant community leader to act as a lay project collaborator and project steering group member.

ENGAGEMENT:

Open theatre simulation

This touring demonstration shows the public the latest minimally invasive surgery. Professor Roger Kneebone and his team from ICCSS (Imperial College Centre for Engagement and Simulation Science) have developed a pop-up operating theatre which visits festivals and events to engage public audiences in discussions about new surgical techniques. Their current research focus is on simulated surgery. Using novel simulation approaches, they provide different audiences with unique insights into research, new technology such as the iKnife, and a glimpse into what it might be like to have an operation, demystifying the process of surgery.



Monitoring and learning

Improving awareness and understanding of PPI and PE with training and resources for researchers, patients and public representatives is of paramount importance. We track involvement and engagement activities to enable sharing of good practice, evaluation and review; we also plan to implement new standards and tools. Two examples of particular importance for sharing good practice are presented below.



INVOLVEMENT:

Cancer patient group

This well-established and active patient group, facilitated by Kelly Gleason, Cancer Research UK senior research nurse (Surgery and Cancer), provides support to research projects and service development with a wide range of involvement activities. Twelve current and former patients meet regularly with clinical staff and researchers. They discuss and support research projects across their different stages, such as reviewing patient material for clinical trials, commenting on publications, supporting protocol development, grant applications and submissions to ethics committees.



This group also plays an active role in collaborative and patient-led initiatives, such as producing videos about the types of cancer research at Imperial. Other initiatives are artistic, i.e. a patient-led public engagement art project. Rina Dave has metastatic breast cancer and produced a moving photographic project with support from Cancer Research UK. She commissioned portraits for an exhibition entitled 'The people who are keeping me alive', which included healthcare professionals photographed to show them as people not simply professionals.

ENGAGEMENT:

Imperial Festival



The Imperial Festival is held every spring to offer members of the public the chance to experience some of the latest developments in research. Health researchers have developed many ingenious ways of engaging adults and children at the Festival. Interactive displays have included:

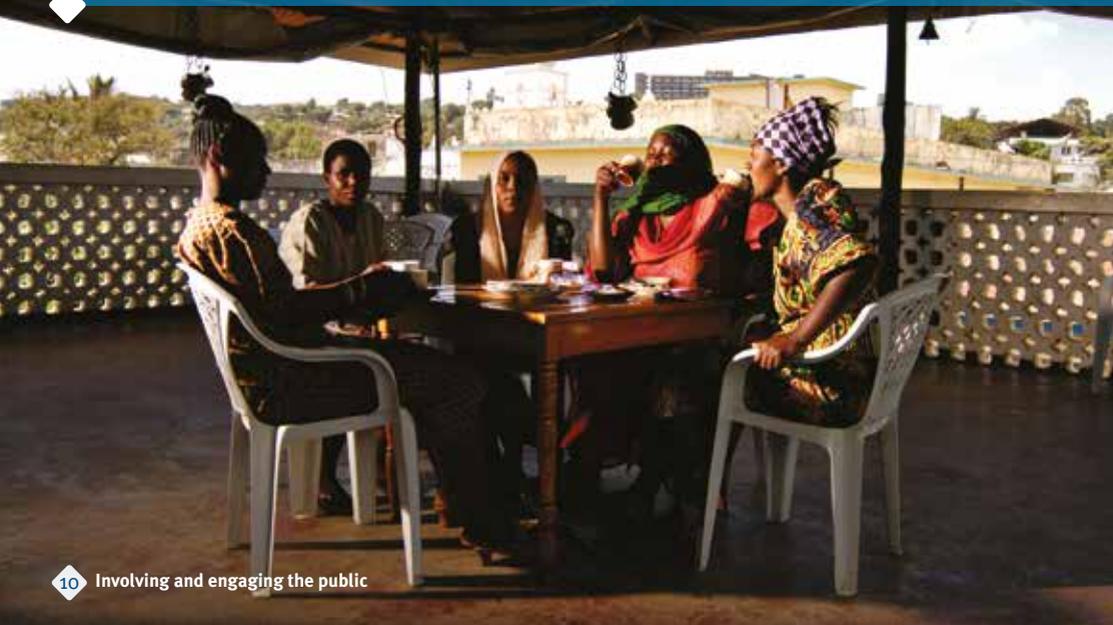
- **How to stop small babies getting ill** – visitors were invited to handle a vacuum-packed placenta as part of learning how it nourishes the foetus in the womb and contributes to the baby's immune system.
- **Sequencing and diagnosis** – magnetic DNA was developed to explore how genome sequencing can help diagnose disease.
- **Not just a fluke** – visitors measured the stiffness of their liver with a fibroscan, a non-invasive device, to find out the condition of their liver.
- **Changing genome gears** – members of the public raced toy cars round an 'epigenetic track' to find out how surroundings affect a person's genes.
- **Bugs and drugs** – visitors were asked to observe feeding bacteria to find out what interactions go on between them and drugs in the gut.

Collaborating

Working in partnership is critical to improve the coordination of PPI and PE. We see collaboration operating at three main levels: internal, local and national/international. The examples below demonstrate strong partnerships and alliances with patient and community groups as well as other organisations.

INVOLVEMENT: CHERUB

CHERUB (Collaborative HIV Eradication of Viral Reservoirs: UK BRC), led by Dr Sarah Fidler, Infectious Diseases, provides a unique experimental medicine approach to new HIV therapeutic strategies. From the start, CHERUB has worked with people living with HIV in the development of protocols and has included patients on steering committees and trial management groups. Lay experts and organisations have been involved in the design of information leaflets, writing articles for peer community publications, and organising patient feedback meetings. Active patient involvement has ensured a strong social media presence, and the CHERUB website has a patient area for referral from individuals interested in research streams and a Twitter account.

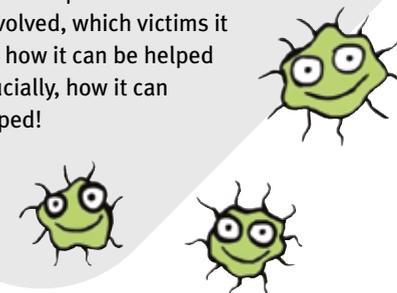


ENGAGEMENT:

How to catch flu



A short animated film produced in 2014 by the MOSAIC (Mechanisms of Severe Acute Influenza Consortium) project led by Professor Peter Openshaw, National Heart and Lung Institute. Steven Appleby, the renowned illustrator, and Pete Bishop, the film-maker, were commissioned. The film's narrator is a flu virus that gives a comical and slightly macabre account of flu's history and its possible future. The virus sits in an armchair to explain to viewers how it has evolved, which victims it prefers, how it can be helped and, crucially, how it can be stopped!



INVOLVEMENT:

IMPRESS

IMPRESS (Inpatient Medication and Patient Relationships – Electronic Systems) has actively engaged patients and lay people in setting up the study, collecting data through observations on hospital wards and analysing the study findings. Interviews have also been conducted to explore both the lay members' and researchers' experiences of lay involvement in data collection. The project is led by Professor Bryony Franklin, Centre for Medication Safety



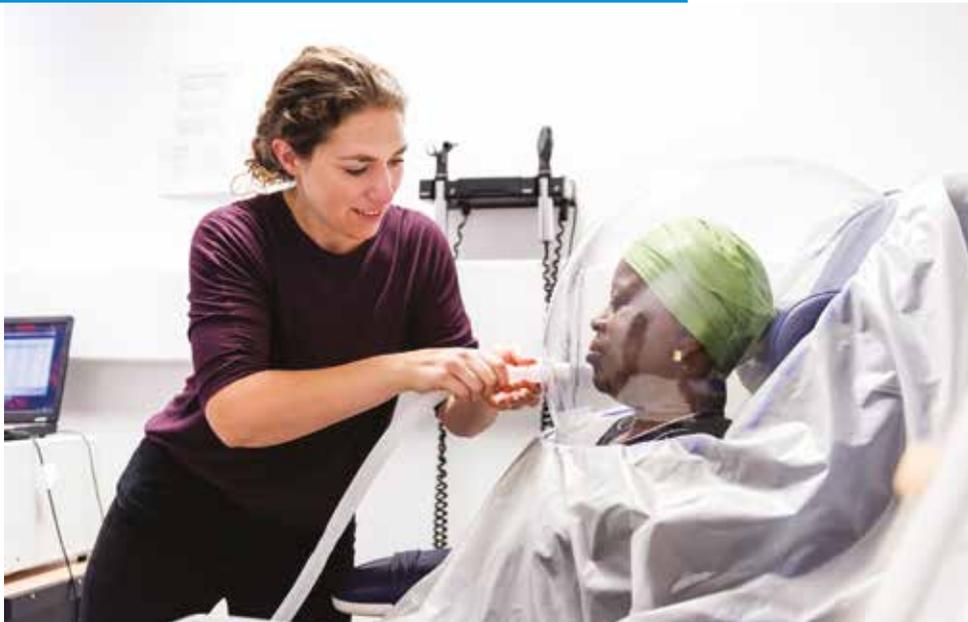
and Service Quality (CMSSQ), a joint research unit between Imperial College Healthcare NHS Trust and UCL School of Pharmacy. It is supported by the Health Foundation, an independent charity working to continuously improve the quality of healthcare in the UK. The IMPRESS study explores the involvement of hospital inpatients in medication safety to see how this may change with the introduction of inpatient electronic prescribing.

Assessing the impact of involvement and engagement

We are using demonstration projects to assess the impact of involvement and engagement, and working with partners to develop research to deepen our understanding of the role of such activities in translational research. The examples below demonstrate efforts to capture the impact of involvement and engagement.

INVOLVEMENT AND ENGAGEMENT:

Reflections on research



A collaborative initiative between local research organisations and patient groups produced a short film for patients and the public. Four patients talked about their involvement in research and also their participation in research. They described their experiences and motivations, thus providing qualitative accounts of their experiences.

ENGAGEMENT:

Heart and lung repair shop



This pop-up shop was installed in the Kings Mall, Hammersmith, in July 2014. Members of the public could chat to scientists working on heart and lung research and use interactive exhibits to explore ways of repairing damaged hearts and lungs. This interactive hub is another innovative example of public engagement, led by Professor Sara Rankin and Ellen Dowell in the National Heart and Lung Institute. The impact of these activities was formally evaluated and a report has been written.

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Principal photography: Imperial College London. Additional photography: page 6 (Migrant health) and page 11 (IMPRESS), NHS Photo Library; page 8 (Cancer patient group), Rina Dave.

