

Patient Experience Research Centre

Public Involvement Newsletter

Welcome to the first issue of the Imperial Patient Experience Research Centre, Public Involvement Newsletter for 2022.

In this newsletter we share upcoming opportunities to get involved in health research, the latest research updates from our Centre and upcoming events which you might be interested in joining.

Upcoming opportunities



Help shape research into personalised diet

Researchers at Imperial College, London are inviting people with a heart condition or at risk of one to provide their views about how to make their diet personalised for them.

What is involved:

You will be asked to attend four meetings, during which you will be asked to share your views on different aspects of the research project, including motivators and barriers to following dietary advice.

When and where:

The four meetings will occur across May 2022 - January 2023 and will be arranged either in person (Imperial College Hammersmith campus - Du Cane Rd) or online via Zoom or Teams. Each meeting will last for 1.5 hours.

Payment:

You will be paid: £37.50 per 1.5 hours (plus travel expenses for face-to-face meeting or £5 Wi-Fi/data expenses for online meeting)

Find out more and register your interest via the button below by **15th April 2022**.

[Get involved](#)



Share your experiences of remote GP consultations

Researchers at the Imperial College, London are inviting individuals to share their experiences of remote GP consultations for new health problems.

Who can get involved:

Adults (over 18 years old) who have attended a GP telephone or video appointment for a new health problem (a problem you have not previously sought healthcare advice or treatment for) in the past 6 months.

At this stage in the recruitment process, the research team are prioritising members of the public who identify as male or non-binary who are currently underrepresented in the study.

What is involved:

You will be asked to participate in a one-to-one online interview

(approx. 45 – 60 mins) with one of the researchers.

When and where:

The interviews will take place online via Zoom teleconferencing software (or an alternative mode, if required) across April 2022 on a date/time of your choosing.

Payment: Those who take part will be offered £15 plus £5 for remote working expenses.

Find out more and register your interest the button below by **15th April 2022**.

[Get involved](#)



Help shape research into outcomes after stroke

Researchers at [Imperial College's Helix Centre](#) are developing next-generation technologies that will help people in their rehabilitation after stroke. They are looking for people who live in London that have had a stroke that affected their arm to help inform this exciting new technology.

What is involved: The team are looking for in person contributions from stroke survivors to help us improve our technology. This will involve wearing wrist-based sensors and motion trackers during a 2 hour session at Imperial's White City Campus to carry out tasks of daily activities such as; using a knife and fork, reading a book and more. We will then record this data to improve the technology.

Who can get involved: Stroke survivors with an arm impairment (18+ years old, living in London and over 6 months post-stroke)

When and where: In-person at Imperial's White City Campus (exact venue and date TBC)

Payment and support: This is a paid opportunity at £25/hr, with accessibility needs accounted for, as well as £10 contribution towards your travel. We will work with you to make sure you are best supported to attend your OnTrack session.

Find out more and register your interest the button below by **10th April 2022**.

[Get involved](#)



Join the VOICE Global community

VOICE is an online platform which brings together members of the public, patients and carers who want to influence and inform UK health research and innovation.

Imperial joined VOICE in January 2019, with the ambition to improve the way we involve patients and members of the public in our research. The public are at the heart of what we do, so ensuring your involvement, engagement and participation in research is a key priority for us. Through VOICE, we hope to capture the wealth of experience and valuable perspectives that individuals and communities can offer on the way our research is designed and delivered.

On the VOICE platform you will find opportunities for involvement, engagement and participation as well as upcoming events relating to health and social care.

To keep updated with the latest VOICE opportunities and help to

influence and inform our research, sign up today via the button below

Join VOICE



Join our North West London Research Involvement Network

Do you live, work, study or receive care in North West London?

We are inviting individuals in our local community to join our online Research Involvement Network to help develop, shape, inform and influence health research undertaken by Imperial College London & Imperial NHS Trust which is focused on improving health outcomes in the North West London community.

As a member of the network you can expect updates on research relevant to the North West London area, invitations to public events as well as the opportunity to share your views and experience via polls, surveys, discussion groups and workshops relevant to health and health care services in North West London.

To join the network please click the button below

Join the network

Upcoming events



Science of Digestion Community Event Tuesday April 26th 2022 (5.30pm to 7.30pm BST)

This exciting free event being organised by [Guts UK](#) and the [NIHR Imperial Biomedical Research Centre](#) is open to anyone with an interest in gut health. The event will give you the opportunity to learn about the hidden world inside you, discover the latest research developments, meet the experts, ask your questions about gut health and share your views on gut health research.

- "500 functions of the liver"
- "Your gut microbes: not bad, just misunderstood"
- "Irritable Bowel Disease – Where have we come from and where are we going?"
- "Diet and your Colon: What's Important?"

Venue: Victoria Hall, Ealing Town Hall Ealing Broadway, Ealing, London W5 2BY

[Click here to find out more and register to attend on Eventbrite](#)

Written Portraits: A poetry performance and discussion 23rd May 2022 (12.00 - 13.00 BST)

Hear the stories of patients and staff at a typical London hospital, told through the poems of Di Sherlock.

[Click here to find out more and register to attend here](#)

Great Exhibition Road Festival 18 - 19th June 2022

Come along to the Great Exhibition Road Festival for an annual celebration of science and the arts with free events for all ages.

Venue: Great Exhibition Road, South Kensington

Keep up to date: [Sign up to the Imperial events emails](#) to get updates about the Festival and other public events or follow us [@ExRdFestival](#) on [Instagram](#), [Facebook](#) and [Twitter](#) for the latest Festival news and events.

You can keep up to date with upcoming Imperial events on the [What's On page](#) and catch up on previous events on the [Imperial YouTube Channel](#)

Public involvement and engagement news & updates



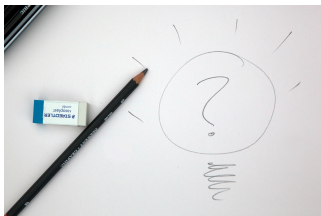
New podcast showcasing PERC HIV Peer Research

Vas Papageorgiou (PhD student at the Patient Experience Research Centre) was invited by Positively Effect (a HIV non-profit organisation in Canada) to share her experiences of conducting a HIV peer research project exploring the impact of COVID-19 on people living with HIV in the UK as [part of their podcast series, 'Pozcast'](#).

On the podcast she is joined by Hussein Hamza one of the peer researchers on the project, who is also a community advocate, and the co-founder and director of Red Ribbon Living Well, a volunteer-led community organization for people living with and affected by HIV. As part of the peer research project, Hussein undertook research training which enabled her to conduct interviews with people living with HIV as part of the study and was also involved in the analysis of the interview transcripts. She is now helping to share the learnings and findings from the study.

The episode title is *Peer Research across the pond: a fascinating UK study exposes barriers and bias bolstered by the pandemic* and is available via the button below.

[Listen to the podcast](#)



Catch up on our latest blogs

Our PERC blog showcases public involvement and engagement activity across Imperial College London. You can click the links below to take you to each of our recent blogs:

[Can humans beat computer models at predicting the spread of COVID-19?](#): Nikos Bosse, PhD Student in Infectious Disease, Centre for the Mathematical Modelling of Infectious Diseases (CMMID) at the London School of Hygiene & Tropical Medicine/NIHR Health Protection Research Unit (HPRU) in Modelling and Health Economics at Imperial College, London

[Involving women to help shape a project exploring pregnancy care following weight-loss surgery](#): Dr Saleem Ansari, Registrar in Metabolic Medicine and Chemical Pathology, working within the Department of Metabolism, Digestion and Reproduction, Imperial College London

[National HIV Testing Week: Give HIV the Finger!](#): Vas Papageorgiou, Flav Coukan, Jane Bruton, Patient Experience Research Centre, Imperial College, London

[Involving parents and carers in research about children's healthcare experiences during COVID-19](#): Dr Kimberley Foley, a Postdoctoral Research Associate working within the Child Health Unit, Department of Primary Care and Public Health. Imperial College London

[Why has nobody asked us?! Our journey so far to co-produce research](#): Dr Helen Skirrow, National Institute Health Research Clinical Doctoral Research Fellow, Child Health Unit, Department of Primary Care and Public Health, School of Public Health, Imperial College London and Lena Choudary-Salter, Founder and CEO of The Mosaic Community Trust

[Reflections on developing and running a Science Café at the Cancer Research UK Imperial Centre](#): Kelly Gleason, Lead Nurse at the Cancer Research UK Imperial Centre



Want to learn more about public involvement in research?

Sign up to our online course on [Public Involvement in Research](#) on Coursera. The course is aimed at researchers but is also suitable for patients and the public to complete.

The course is set over four weeks (although you can go at your own pace) and introduces the concepts of public involvement and co-production in health research as well as discussing in more detail the role of public involvement across the research cycle.

[Find out more](#)

Research News



COVID-19 human challenge study reveals detailed insights into infection

In February 2021, it was announced that the UK would be the first country in the world to carry out a human infection study (also known as a human challenge study) with SARS-CoV-2, the coronavirus that causes COVID-19.

During this study, healthy male and female volunteers aged 18-30 years, unvaccinated against COVID-19 and with no prior infection with SARS-CoV-2 were given a low dose of the virus – introduced via drops up the nose – and then carefully monitored by clinical staff in a controlled environment over a two-week period. The study used virus from very early in the pandemic, prior to the emergence of the Alpha variant and aimed to learn more about the infection and test new vaccines and treatments in the future.

The initial findings from the study have now been released as a “preprint” entitled the “[Safety, tolerability and viral kinetics during SARS-CoV-2 human challenge](#)” and is now available at: . A preprint is a preliminary version of a manuscript for a scientific journal that has not yet been peer reviewed by other researchers. We note that the publication of a preprint should not be taken as an endorsement of its validity as established information or for guiding clinical practice.

Among several key clinical insights, researchers found that symptoms start to develop very fast, on average about two days after contact with the virus. The infection first appears in the throat; infectious virus peaks about five days into infection and, at that stage, is significantly more abundant in the nose than the throat.

They also found that lateral flow tests (LFTs) are a reassuringly reliable indicator of whether infectious virus is present (i.e., whether they are likely to be able to transmit virus to other people).

Learn more:

- [Read the plain English summary of the initial findings.](#)
- [Read the full Imperial news article](#)
- [Read our pre-print article on public attitudes towards the acceptability of a human challenge trial in the UK](#)



Keep up to date with our COVID-19 Research

There is now a national, and global, commitment to enhance our scientific understanding of Long COVID, as well as improve the care, support and treatment available to those affected. Imperial College London is one of the groups that have been awarded funding from UK Research and Innovation (UKRI) to research Long COVID.

Our study, called REACT-Long COVID (REACT-LC) builds [upon Imperial's REACT \(REal-time Assessment of Community Transmission\) study](#) and will explore people's experiences and journeys with Long COVID, as well as look to understand the role that our genes, health, environment, and demographics may play in the development and duration of this condition.

You can watch our latest video, explaining more about the REACT-LC study [here](#).

To keep up to date with our ongoing research, you can:

- Join the '[REACT: COVID-19 Community Network](#)' on the [VOICE-global.org platform](#), an online platform for public involvement and engagement in health research. As part of this group you will receive updates on any new findings from REACT/REACT-Long COVID, as well as invites to public engagement and involvement activities.
- By signing up to VOICE, you will also have access to [our Long COVID Research Involvement Hub](#) (make sure you select 'Long COVID' as one of your interest areas when signing up to VOICE). A newly launched platform which provides a space for patients and researchers to connect to influence, co-create and share ongoing research into the long-term effects of COVID-19. We are currently inviting research teams across the UK exploring long-term effects of COVID-19 to use this platform to share opportunities to get involved or take part in their projects, as well as the latest news and events.

Contact us:

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