

## Patient Experience Research Centre

### Public Involvement Newsletter

Welcome to the August issue of the Imperial College, London Patient Experience Research Centre Public Involvement Newsletter.

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

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## Upcoming opportunities



### Exploring the acceptability of healthcare innovation within the NHS

Researchers at Imperial College, London are inviting individuals to share their views on various healthcare innovations, including your perceptions on how beneficial they might be and how suitable they are to be used in the UK, particularly in the NHS.

**Who can get involved:**  
Adults (over 18 years old)

**What is involved:**  
You will be asked to attend a 15-minute presentation (either virtually or in-person) which will introduce you to three different healthcare innovations. You will then be asked to take part in a 1-to-1 conversation that will last max. 1 hour, where you will be asked a number of questions about your views of the innovations presented.

**When and where:**  
Presentations and interviews will be organised at a 1.15 hr time slot preferable to you between Sept 2022 and Mar 2023. The interview will take place directly after the presentation and you may choose to attend the presentation and interview either virtually (via Microsoft Teams) or in-person (at one of the following hospitals: Hammersmith Hospital, Queen Charlotte's & Chelsea Hospital, St Mary's Hospital, Western Eye Hospital or Charing Cross)

**Payment:**  
Those taking part will receive reimbursement in accordance with NIHR Centre for Engagement and Dissemination Guidelines (£25 per hour)

Find out more and register your interest the button below by the **31st October 2022**.

[Get involved](#)



### Join the Cytomegalovirus (CMV) Research Steering Group

CMV is a member of the herpes virus family and is spread through contact with saliva, blood, breast milk, semen and urine. CMV will infect most adults during their life. Healthy individuals rarely show symptoms. However, CMV can result in serious health complications and even death for those with weak immune systems, such as transplant

recipients. CMV is also the leading viral cause of disease if it infects the fetus during pregnancy. This can cause permanent disabilities, such as learning difficulties, blindness, deafness, or even death.

The London In-Vitro Diagnostics Cooperative (London IVD) is looking for **parents whose children have been affected by CMV** to share their personal experience to inform the development of a rapid, low-cost CMV diagnostic test.

**What does the role involve:**

Attending research steering group meetings (usually 2h) every 6 months for a year and half. Meetings will be held online.

**Reimbursement:**

You will get paid in line with NIHR Centre for Engagement and Dissemination Guidelines (£25 per hour)

For further information and to express your interest please contact [londonivdcoop@imperial.ac.uk](mailto:londonivdcoop@imperial.ac.uk) by Friday **16th September 2022** briefly outlining your experience related to CMV.



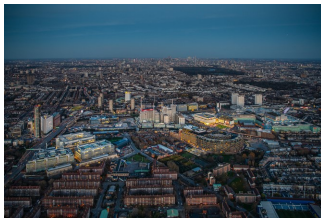
## Join the VOICE Global community

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 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





## Adult Education Evening Classes - Enrolling for Autumn 2022

Imperial College's adult education programme, [Imperial after:hours](#) is now open for enrolment for courses starting October 2022 and everyone is welcome!

We have a wide range of courses in languages, practical arts, humanities and science, for beginners and the more advanced. Many of our courses are back face-to-face, but we have also maintained many online courses.

There is an early bird discount available to everyone for many courses if you enrol now, and there are additional discounts for various groups from students to tutors, local residents of Kensington and Chelsea (Local residents please apply from an address with a SW3, SW5, SW7, SW10 or W8 post code), NHS workers and teachers, amongst others – [click here for discount fees](#) and find out more via the button below.

[Find out more](#)

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## Upcoming events



### **Online Seminar: New insights into understanding and treating obesity** **Tuesday 6th September 2022 (12.30 - 13.30 BST)**

Two experts from Imperial College Healthcare NHS Trust will present their work on new insights into understanding and treating obesity in this online event.

[Click here to find out more and to register your free place](#)

### **Imperial College Undergraduate Open Day** **Saturday 17th September (from 9.30am)**

The open day provides an opportunity for young people considering Imperial College as their University to explore the different academic departments and hear more about life at Imperial.

[Click here to find out more and to book your place](#)

### **Mis(s)diagnosed - why sex matters in cardiovascular diseases** **Tuesday 27th September 2022 (15.00 – 18.00 BST)**

This event, being led by the Imperial College, London British Heart Foundation Doctoral Training Partnership, aims to raise awareness and highlight sex as an important consideration in all biomedical research areas, in this case particularly cardiovascular diseases.

[Click here to find out more and register your free place](#)

### **White City Community Campus Tours** **Ongoing (running on the second Wednesday of every month at 1pm; tea & coffee from 12.30pm)**

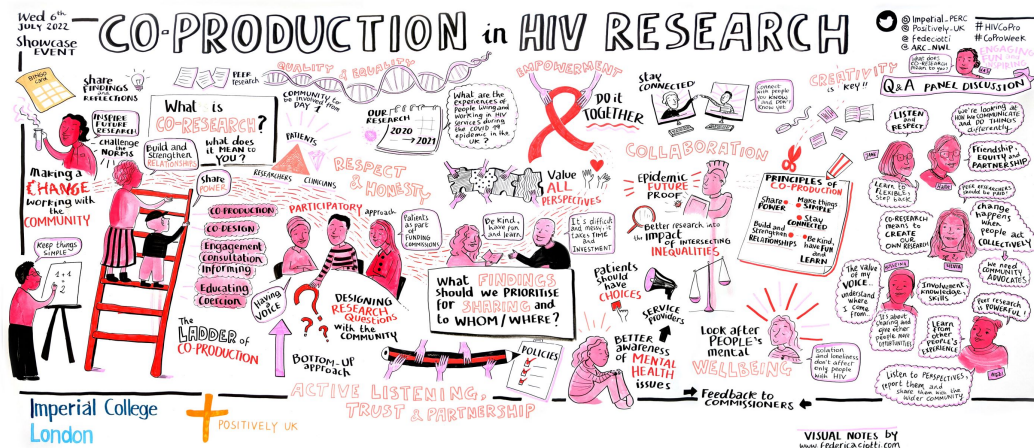
Tours include a visit to one of the White City research teams, The Invention Rooms (our community engagement and Makerspace) and to Scale Space (our new space for innovative business). The tour

lasts 1 hour and follows an accessible step-free route.

[Click here to find out more and register your free place](#)

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 video showcasing HIV Participatory Research Project

On Wednesday 6 July 2022, 25 stakeholders met at Lift, Islington (a community venue) to reflect, create and share ideas together as a group about co-producing HIV research using the example of a recent participatory project exploring the impact of COVID-19 on people living with HIV in the UK.

The showcase event was co-designed to be interactive and participatory in nature (after all, we wanted to showcase how valuable these approaches can be to research!). You can find out more about how we co-designed the day in our blog [HIV Co-Production Showcase: Sharing learnings from a participatory research project \(Part 1\)](#), and featured a number of creative activities and discussion throughout the day, including our co-production principle collages shown in our [follow-up blog](#).

Our discussion across the event, was also captured throughout the day by our amazing visual notetaker [Federica](#) – you can see the final product above.

Lastly, we are excited to showcase our video which was created following the event by our fantastic filmmaker, [Ed Rolfe](#), and features several of the team sharing their reflections of working together and co-production.

This event, and all our work so far, has been a huge learning curve for the team. We have learned the art of keeping things simple and how co-production, when done properly and in a respectful way, can really help to make research more accessible to everyone. We have built friendships with our co-researchers and can't wait to see what the future holds for both the project and our co-researchers!

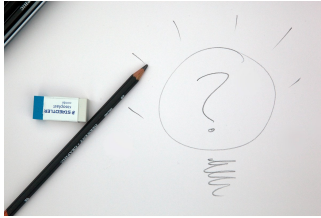
For more on our work so far and for future updates please visit our [project webpage](#).

[Watch the video](#)

### 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:

[People's Research Cafe Blog Series: Understanding the](#)



### [relationship between diet and gut health](#)

Maria Valdivia-Garcia (Research Associate), Maria Glymenaki – (Research Associate), Miss Yang Bi (PhD student), Jia Li (Reader in Biological Chemistry) from the Department of Metabolism, Digestion and Reproduction

### [HIV Co-Production Showcase: Sharing learnings from a participatory research project \(Part 1 & Part 2\)](#)

Members of the Patient Experience Research Centre and Positively UK

### [User-centred design in diabetes technology development](#)

Dr Parizad Avari, ST7 Registrar and Honorary Clinical Lecturer

### [Dying Matters Week: Ensuring you and your loved ones are #InAGoodPlace at the end of life](#)

Adam Lound, Research Physiotherapist

### [How patients at different stages of the steroid weaning process helped to shape and design my research](#)

Dr Katherine Lazarus, Diabetes and Endocrine Registrar and Clinical Research Fellow



## 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



### Learning from the pandemic in real-time - 5 things Imperial's REal-time Assessment of Community Transmission (REACT) study has taught us

Three million, four hundred and eighteen thousand, seven hundred and eighty-eight. Since Imperial's REACT study began little over two years ago, that's the number of people up and down the country who've taken part in the programme, swabbing their noses for the virus or pricking their fingers to see if they'd likely had coronavirus before.

That makes it one of the world's largest coronavirus monitoring studies, and the biggest unique study participant group in existence in the country. Getting a study of this size and scope off the ground was a formidable task, especially for a small group that formed virtually overnight as infections with a barely known virus were gripping the country back in April 2020.

They had a helping hand. Ipsos, a global leader in market research, were the study's logistical partners, dealing with everything from sending out over 17million invite letters, to organising the refrigeration system to keep the samples cold in transit.

After two years of data collection, REACT has now finished, but the lights aren't off for the study.

While the future of REACT is yet to be written, its legacy is already carved out from the impact it has made on science and understanding of the virus and its consequences. We look back at some of these major contributions in this article and unravel five of the most important things we've learned from the study.

Learn more:

- [Read the full Imperial news article here](#)



## Get the latest updates on the REACT Long COVID study

The REACT Long COVID update report provides an overview of the research and involvement activities linked to the REACT Long COVID study. It summarises our findings so far as well as our next steps.

It has been developed following feedback from our public advisors who highlighted that more needs to be done to keep the public up to date with the work we have been doing. Read and download the report at the bottom of our webpage.

Read and download the report [here](#) (you will need to scroll down to the bottom of the webpage) .



## Keep up-to-date with our COVID-19 and Long COVID 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 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 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). The hub 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 hub to share opportunities to get involved or take part in their projects, as well as the latest news and events.
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**Contact us:**  
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