

# Patient Experience Research Centre

Public Involvement Newsletter

Welcome to the November 2022 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, an exciting research funding update as well as upcoming events which you might be interested in joining.

## Upcoming opportunities



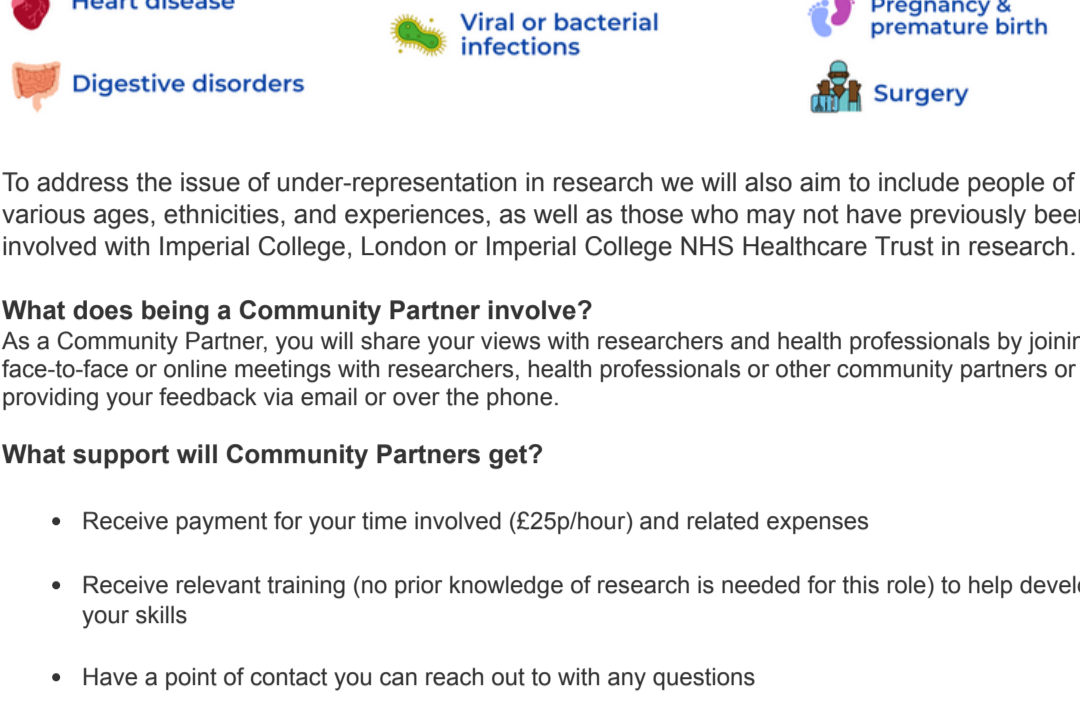
**We are looking for people in North West London to share their valuable lived experience of health with researchers to help improve the health of the local community.**

This is a paid role and will take up to 30 hours of your time from February 2023 for 12 months, with the possibility for extension.

### Who can be a Community Partner?

Anyone who:

- is aged 17 years or older
- lives, works, or studies in North West London (this includes the boroughs of Brent, Ealing, Kensington & Chelsea, Hammersmith & Fulham, Harrow, Hillingdon, Hounslow or Westminster)
- has community connections in North West London (such as belonging to a church group, youth group, residents' group, charity or any other formal or informal community-based organisation/group)
- has current experience (as a patient, carer, or family member) related to one or more of the following areas:



To address the issue of under-representation in research we will also aim to include people of various ages, ethnicities, and experiences, as well as those who may not have previously been involved with Imperial College, London or Imperial College NHS Healthcare Trust in research.

### What does being a Community Partner involve?

As a Community Partner, you will share your views with researchers and health professionals by joining face-to-face or online meetings with researchers, health professionals or other community partners or by providing your feedback via email or over the phone.

### What support will Community Partners get?

- Receive payment for your time involved (£25p/hour) and related expenses
- Receive relevant training (no prior knowledge of research is needed for this role) to help develop your skills
- Have a point of contact you can reach out to with any questions

### Where can I find out more about the role?

For more information about the role go to our [website](#) or watch our [video about the role](#).

To express your interest in being a Community Partner please complete our sign-up form (via the button below) by the 9<sup>th</sup> of January 2023.

[Apply to be a Community Partner](#)



### Join the Imperial Health Knowledge Bank Steering Group

The Imperial Health Knowledge Bank (IHKB) is a collection of health data and blood samples from Imperial College Healthcare NHS Trust patients. The patients included in the database are interested in taking part in research studies and have provided consent for their blood samples to be used for research and teaching purposes. The IHKB is seeking a community partner to join its steering group, which guides the progress of their activities.

#### Who are we looking for?

We are looking for someone 25 years old or above, who lives, works or studies in North West London to share their views on the activities of the IHKB.

#### How much time is required for the role?

The role will involve attending steering group meetings virtually once a month, with each meeting lasting for up to two hours.

#### Will you be paid for the opportunity?

Yes! We will pay you £25 / hour for your time and cover any additional relevant expenses.

#### Why should you sign up for the opportunity?

You will be able to play a key role in supporting the IHKB to improve the health of the local community, as the health data which is collected helps to identify diseases early, improves outcomes and gain more understanding of the genetic and environmental cause of diseases, and why they develop.

#### How do I apply for this opportunity?

To apply, please fill out this expression of interest form via the button below by **Sunday 4 December 2022**.

#### What happens after you apply?

To address the current issue of under-representation in research, we will also be reviewing applications to the opportunities below against a diversity and inclusion criteria, that includes involving people of different ages, ethnicities and backgrounds, and involving those who may not have previously been involved with Imperial College, London or had involvement in research.

Those who express their interest in the role can expect to receive an update by 9 December 2022.

Those who meet the eligibility criteria will be asked to join a short phone/video call at a time that is convenient for them to hear more about the role and their experiences.

For any queries please contact us by emailing [publicinvolvement@imperial.ac.uk](mailto:publicinvolvement@imperial.ac.uk) or call us on 020 7594 9774

[Find out more & apply](#)



### Improving HIV prevention services for Black women in England

Researchers at the Patient Experience Research Centre, Imperial College London are investigating ways to improve the access of a new HIV prevention, HIV Pre Exposure Prophylaxis (PrEP), in England for Black women.

PrEP is a drug taken by someone who is HIV-negative before and after sex that reduces the risk of getting HIV.

#### What is involved?

You will be invited to two sessions to discuss:

- your thoughts on the barriers and facilitators to PrEP access in England (up to 90 minutes; online/in-person) and
- recommendations to address those factors (up to 3 hours; in-person)

#### Who can be involved?

Anyone who:

- identifies as a woman of Black Ethnicity
- is over 18 years old
- lives in England
- is HIV-negative or unknown HIV status

You can be involved regardless of whether you have used PrEP or not

#### Do I get anything for taking part?

Each person involved will receive a £50 reimbursement and reasonable travel and carer expenses will also be covered.

#### How do I express my interest in taking part?

Please contact Flavi at [flavi@imperial.ac.uk](mailto:flavi@imperial.ac.uk) to find out more and to express your interest



### Share your views on the use of routinely collected blood samples during pregnancy in a short survey

Blood samples are given by every woman having NHS pregnancy care and are stored for 2 years in case women are exposed to an infection which may affect the mother or baby. If this happens, the samples can be tested for antibodies to determine if the woman already has immunity from the virus.

Researchers at Imperial want to explore how these samples, which would otherwise be thrown away, can be used to benefit the women who give them, their families and their communities. However, it is critical that women giving these samples are central in determining how these samples might be best used.

To capture the views of women, the research team have developed a short online survey which will take approximately 10 minutes to complete.

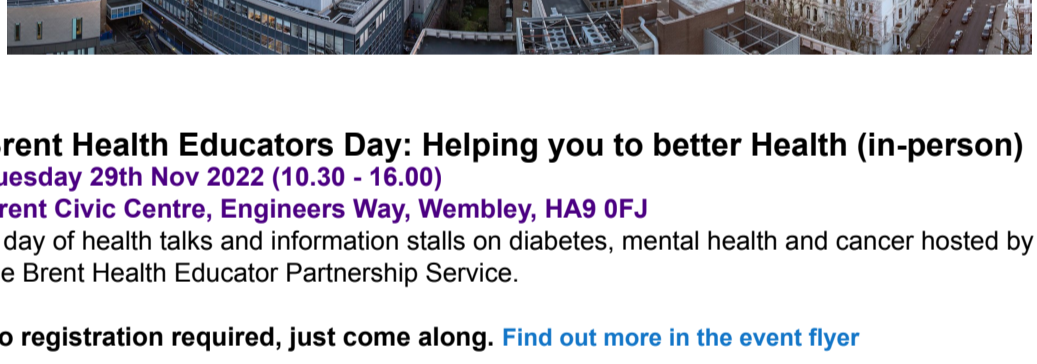
#### Who can complete the survey?

The survey is open to any woman or person planning pregnancy or who has been pregnant.

**Deadline:** 31st December 2022

[Go to the survey](#)

## Upcoming events



**Brent Health Educators Day: Helping you to better Health (in-person)**  
**Tuesday 29th Nov 2022 (10.30 - 16.00)**  
**Brent Civic Centre, Engineers Way, Wembley, HA9 0FJ**  
 A day of health talks and information stalls on diabetes, mental health and cancer hosted by the Brent Health Educator Partnership Service.

No registration required, just come along. [Find out more in the event flyer](#)

**Imperial Lates: Look up to the skies (in-person)**  
**Thursday 8th December 2022 (18.00 - 21.00)**  
**Imperial College London College Main Entrance Exhibition Road London SW7 2AZ**  
 Celebrate the 50th anniversary of the last human footprint on the moon and explore the science above our heads through lively discussions, creative workshops and interactive exhibits at this event.

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

**Using Artificial Intelligence (AI) for more effective cancer diagnosis (online)**  
**Monday 12th Dec 2022 (12:00 - 13.00)**  
 Hear from two experts at Imperial College, London on how Artificial Intelligence can be used to improve cancer diagnosis and ask your questions.

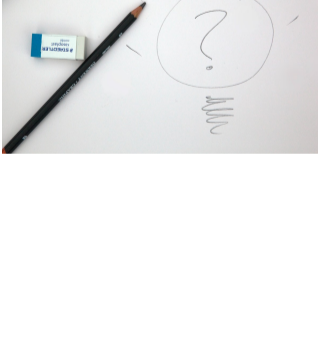
[Click here to find out more and register for your free place.](#)

**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 for 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](#)

## Other updates



### 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: Artificial Intelligence in healthcare: exciting but complex](#)  
 William Bolton (AI4Health Research Postgraduate) & Damien Ming (Clinical Research Fellow), Centre for Antimicrobial Optimisation, Imperial College, London

[People's Research Cafe Blog Series: Analysing patient feedback to improve patient-centred care](#)  
 Sarindi Aiyasinghe (Programme Manager in Digital Health and Patient Experience), NIHR Imperial Patient Safety Translational Research Centre

[People's Research Cafe Blog Series: A coffee for your thoughts: How and when can we personalise medicine?](#)  
 Ellie Van Vogt, (NIHR Pre-doctoral Fellow) Imperial Clinical Trials Unit



### 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.

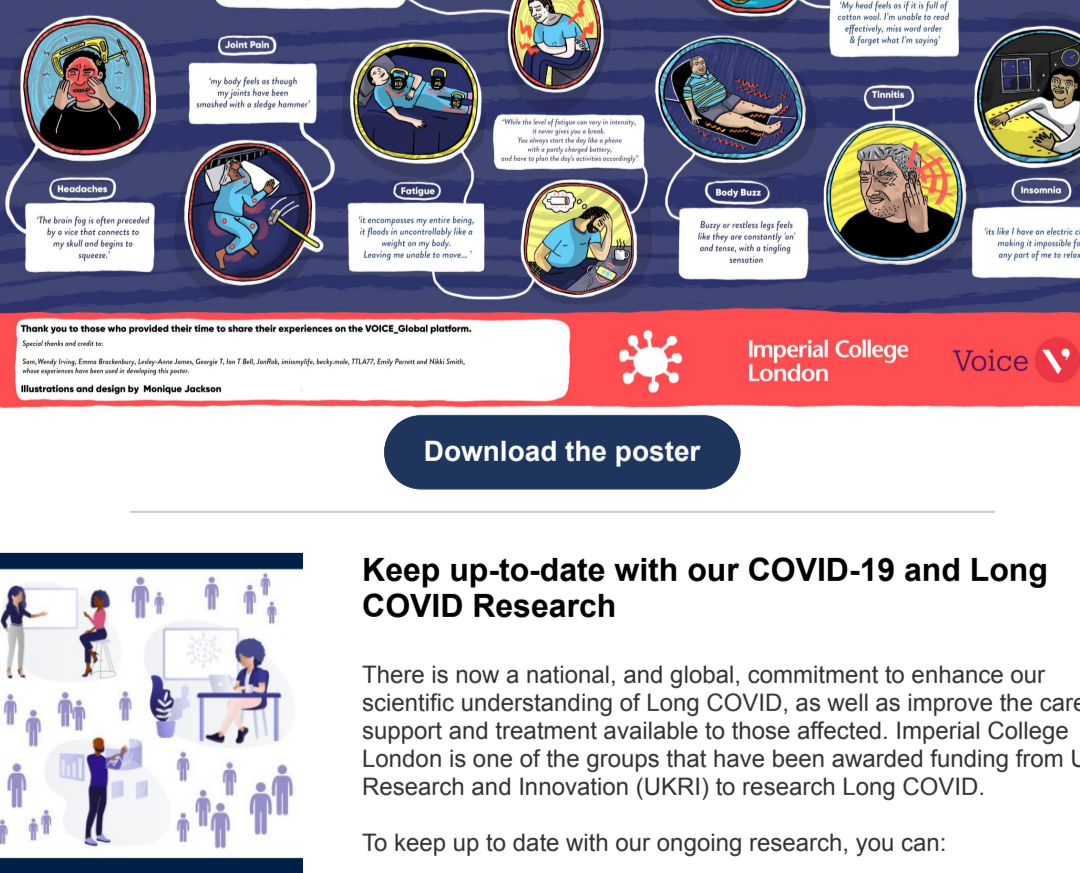
[Find out more](#)

## Defining and Visualising Long COVID

Over the past year, we have been inviting people to share what ongoing symptoms after COVID-19 feel like in their own words as part of our [defining Long COVID Challenge on VOICE Global](#).

We have received over 100 responses which capture the depth and breadth of symptoms experienced. One of our aims of this challenge was to use these responses to raise awareness of the symptoms of Long COVID, and their impact, in a way that is accessible, engaging, and impactful. As such, we have been working closely with [Monique Jackson](#) to develop illustrations which visually capture the range and impact of Long COVID symptoms. The poster includes descriptions of fatigue, joint pain, headaches, breathlessness, insomnia, brain fog and heart palpitations.

While we couldn't include all the responses we received, we are continuing to look at ways to share these responses further and are continuing to invite symptom descriptions [here](#).



[Download the poster](#)

### 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.

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.

**Contact us:**  
[publicinvolvement@imperial.ac.uk](mailto:publicinvolvement@imperial.ac.uk)

**Our mailing address is:**  
 Patient Experience Research Centre  
 St Marys Campus  
 Norfolk Place  
 London, W2 1PG

**Want to change how you receive these emails?**

You are receiving this email as you signed up to the Imperial College London Patient Experience Research Centre mailing list. To unsubscribe from these updates (or edit your preferences), please reply to this email with 'UNSUBSCRIBE' (or 'EDIT') in the subject line.

