

Patient Experience Research Centre

Public Involvement Newsletter

Welcome to the first issue of the Imperial College, London Patient Experience Research Centre Public Involvement Newsletter for 2023.

In this issue we share upcoming opportunities to get involved in health research, as well as upcoming events which you might be interested in joining.

Upcoming opportunities



Become an advisor on a trial looking to improve outcomes after hip replacement surgery

Researchers at Imperial College London are looking for members of the public to join our public and patient involvement group to help us design our trial which will compare recovery and progress post-operation of two hip devices.

Who are we looking for?

We are looking to recruit a diverse group of 10 adults (aged 18 years and older) to join our public involvement group.

We are looking both for people with experience of hip surgery (either as a patient, carer or family member) and those without. For this opportunity you must live in the UK.

What will I be asked to do?

As part of the public involvement group, we would like you to attend 7 meetings over 2 years with our research team. (The meetings will be hybrid, so you can join in-person or remotely.)

Those involved will help us design certain aspects of the trial, support our running of the trial, and help us review findings from the study. Your input will help us design patient-facing documents that are clear and easy for patients to understand and will, more importantly, make sure we are measuring things that are important to patients.

When and what time?

These groups will take place in early 2023. There are no set times, as of yet, however the young person's group will be after school hours.

Those involved will be paid £25/hr for attending meetings. In addition, for those joining remotely, a fee for WiFi/data of £5 will be provided for each remote meeting. If you join the meetings inperson, we will cover your travel expenses and refreshments will be provided.

To apply, please click the button below. The deadline to apply is **Friday 31st March 2023**

For any queries please contact Brogan Guest b.guest@imperial.ac.uk

Find out more & apply



Help design an intervention to support older people and carers with managing their medications

Background:

Carers who are involved in helping their relatives / friends with their medicines sometimes feel left out when their relative / friend is admitted to hospital.

We want to create and design a service to help carers become part of the hospital admission process, and to support communication between healthcare professionals and carers about medicines during a patient's hospital stay and afterwards

What is involved?

Participants will be invited to take part in a co-design workshop with members of the research team.

In the co-design workshops, we will share what we have found out from our earlier work. In that work, we interviewed hospital in patients and their carers about what they believed to be the problems about involving carers during their patients' hospital admissions were and possible ways to address the problems (solutions). In the workshops, we will ask you for your thoughts on the possible solutions.

When and what time?

There are two co-design workshops to choose from

- Workshop 1 (on Zoom): 2nd February 2023 2:00pm 3:30pm
- Workshop 2 (face-to-face): 22nd February 2023 10am-12pm in Central London

You are only required to attend one of these workshops and you will be asked to chose your preference when signing up.

Who we are looking for:

We are looking for people who either are (i) a patient who has an informal carer or (ii) a carer to an adult patient. Who also:

- Live in Greater London
- Are 18 years old or older
- Have experience of a hospital admission in the last 5 years

What support will I receive?

Those involved will receive:

- A £67.50 honorarium for their participation if they attend Workshop 1 (on Zoom)
- A £75 honorarium plus travel expenses if they attend Workshop 2 (face-to-face)

How do I express my interest?

To apply, please click the button below. The deadline to apply is

Sunday 29th January 2023.

Alternatively, those interested can email Shahd via s.abdelaziz@nhs.net

Find out more & apply



Share your views on scientific advice given during COVID-19 to improve future public communications

Background:

During the COVID-19 pandemic, mathematical modelling is a tool that has been widely used to understand what the disease is doing, the effects of disease on society and to try to predict what it might do in the future.

Modelling from many places, including UK Health Security Agency (UKHSA) and academia fed into the government Scientific group and provided an agreed opinion of the modelling to central government, via the Scientific Advisory Group for Emergencies (SAGE). Modelling reports about the COVID-19 pandemic were openly published and accessible on the government website.

The Department of Health and Social Care (DHSC) are very keen to know whether these reports were successful in sharing information to the general public, i.e., whether they were understandable and fit-for-purpose.

What is involved?

Members of the public will be asked to attend a 2 -hour online workshop where they will be asked to read and discuss two modelling reports.

Those involved will be asked to share their views on, the key findings, how the document is written, how figures are presented and suggestions for improvement. In this workshop we will focus on scientific advice contained in the report affecting the short term (i.e. scientific information has an implication for the next days) and long term (i.e. information has implications for the next months).

When and what time?

The 2-hour session will take place online on Wednesday 23rd February at 18:00 - 20:00

Who we are looking for:

Up to 30 people living in the UK.

What payment will I receive?

Attendees will be reimbursed £25 per hour, plus a £5 contribution for WIFI. We will reimburse participants via UKHSA's standard payment process, via bank transfer.

How do I express my interest?

To apply, please click the button below. The deadline to apply is **Friday 10th February 2023.**

Find out more & apply



Provide your views on a spinal cord injury research project

Researchers at Imperial College London would like to speak to people with spinal cord injury (SCI) or their families to ask about whether they think a new research study we have been thinking about would be a good idea.

The study would be about a new way to assess people with spinal cord injury, which could give added information about the health of the spinal cord following injury. We wonder if this might tell us something about whether someone has the potential to recover some muscle action.

Who are we looking for?

We are looking to involve people (18 years and older) with spinal cord injury especially but also the families and carers of people affected by the condition.

What will I be asked to do?

After expressing an interest in being involved, you will be provided with further information about the project and invited to join a 1 hour virtual group call with the researchers to discuss the project in more detail and share their views on it..

Will I be paid for the opportunity?

Yes! We will pay you £25 / hour for your time.

How do I apply for this opportunity?

To apply, please click the button below. The deadline to apply is **Friday 24th February 2023.**

For any queries please contact Dr Rowan Boyles via r.boyles@imperial.ac.uk

Find out more & apply



Take part in a project exploring social relationships and eating disorders

Please note this is a research participation opportunity (i.e. you will be participating in the study rather than assisting researchers to shape/design the study)

Background:

The Child and Adolescent Mental Health team at Imperial College London are currently recruiting young people and parents with lived experiences of eating disorders to better understand how eating disorders can impact social relationships.

Your views will help shape a new social model of eating disorders and new psychological and psychopharmacological interventions or treatments

Who we are looking for:

 3 young people aged 13-15 with anorexia nervosa or bulimia nervosa or anorexia nervosa/bulimia nervosa plus comorbid autism spectrum disorder • 4 parents of a young person with the above.

What would participation involve?

Attending two online focus groups (either of parents or young people). The focus groups will last one hour each and will be one month apart.

When and what time?

These focus groups will take place in early 2023. There are no set times, as of yet, however the young person's group will be after school hours.

What support will I receive?

Participants will receive a £60 e-voucher on completion of both sessions.

How do I express my interest?

More information, including an information sheet and sign-up details can be found via the button below.

Alternatively, those interested can email the study team on FOCUSED@imperial.ac.uk





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 Flav at flavien.coukan15@imperial.ac.uk to find out more and to express your interest



Become a public partner with the National Institute for Health Research

The National Institute for Health and Care Research (NIHR) Patient and Public Involvement and Engagement team (PPIE) is seeking to appoint Public Partners to play a role in the funding processes of NIHR funded Infrastructure and Faculty awards. The NIHR are particularly looking for people to provide input at the funding committee stage, which involves assessing applications and taking part in funding selection committees.

This opportunity is aimed at those with knowledge and/or experience of patient and public involvement in health and social care services research, such as reviewing an application, working with researchers, being part of a research study or sitting on committees/advisory groups.

You can find out more about the role and apply via the button below.

The deadline to apply is 5th February 2023.



Upcoming events



Imperial Lates: Drug Experiments (in-person)

Thursday 9th February 2023 (18.00 - 21.00)

Imperial College LondonCollege Main Entrance Exhibition Road London SW7 2AZ

Take a trip through the science of marvellous medicines, notorious narcotics, and everyday cravings at our latest evening of discovery. From artistic re-imaginings of the brain on psychedelics, to talks on science of microdosing and the under-representation of women in clinical trials, the Lates will bring together leading experts on drug design, development, use and abuse.

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: Developing a new technology to diagnose a virus that can lead to disabilities in new born babies

Dr Shanshan Zhou, Public and Patient Involvement lead, NIHR London In Vitro Diagnostic Cooperative

<u>People's Research Cafe Blog Series: Can a daily food supplement prevent weight gain?</u>

Aisha Anjum, Clinical Trial Manager/Monitor, <u>Imperial Clinical Trials</u>
<u>Unit</u>



Want to learn more about public involvement in research?

Sign up to our online course on <u>Public Involvement in Research</u> 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.





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 <u>VOICE-global.org platform</u>, 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 <u>our Long COVID Research Involvement Hub</u> (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

Our mailing address is:
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