

Patient Experience Research Centre

Public Involvement Newsletter

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

In this issue we share new opportunities for involvement and engagement in research, upcoming events, and highlights from our research.

Involvement and engagement opportunities



Help shape child health research in North West London

The Patient Experience Research Centre are **inviting parents and family caregivers (e.g. grandparents) who care for a child aged between 0 – 12 to complete a short survey** to help inform local child health research.

We are particularly looking for views of parents and caregivers who live or work in North West London, or whose child receives healthcare in this area.

Your responses will enable researchers and health professionals across Imperial College London, and Imperial College Healthcare NHS Trust to ensure the child health research that we do has the greatest impact and relevance to local families and the community of North West London.

You can access the survey via the button below. The survey closes on Sunday 5th September 2021.

[Go to the survey](#)



Have you had a late, missed or incorrect medical diagnosis?

Researchers across Imperial College, London are exploring new ways to analyse biological fluids or tissue samples (known as metabolic phenotyping) to improve disease diagnoses by identifying the most common diseases which have missed, late and/or incorrect diagnoses.

To help inform this work they are inviting individuals who have now received an accurate diagnosis for a medical condition or disease after misdiagnosis or after a prolonged period of not having a diagnosis to complete a short survey (5 minutes).

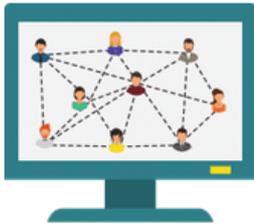
Your response will help researchers and healthcare providers to:

- understand which conditions/diseases are the most difficult to diagnose

- develop diagnostic tests to speed up diagnosis for medical conditions

You can access the survey via the button below.

[Go to the survey](#)



Join a paid online discussion session on weight and fertility research

Researchers from the [Department of Metabolism, Digestion and Reproduction](#) at Imperial College, London are **inviting adults (18 years or older) who have a high body mass index (BMI) or obesity** to join an **online public discussion on 2nd September 2021 (5 - 6.30pm) via zoom** to share your views and help shape research exploring how weight affects both male and female fertility.

During the session you will be given:

- an introduction to the research on weight and fertility undertaken at Imperial College, London
- an opportunity to ask any questions
- an opportunity to share your views in smaller group discussions (split by males and females) to help shape and develop our research in this area.

Payment:

We are offering £42.50 to take part in the 1.5-hour session via Zoom. This payment is based on the National Institute for Health Research payment policy for public involvement and includes a £5 contribution towards data/internet costs that may be used to access Zoom.

How to get involved?

Please click the button below to register using the online sign-up form. You will be asked to answer some questions about your experience and details about yourself (which are optional), which will help us to include as many diverse perspectives as possible in this discussion.

Please email publicinvolvement@imperial.ac.uk with any questions or if you would prefer to register your interest in a different way.

[Sign-up to the session](#)



Help researchers define symptoms of Long COVID by sharing your experience

When carrying out research to understand (and define) a new condition such as Long COVID, it's important that as many views are captured and the different experiences are explored, recognising that the experience of symptoms may be different for each person.

We are therefore inviting individuals with ongoing symptoms after

COVID-19 to share what these symptoms feel like in your own words (or pictures) to help inform the REACT long COVID research at Imperial College London.

You can get involved, read what others have said and share your own response via the button below.

Please note, you do need to create an account to post, please get in touch with publicinvolvement@imperial.ac.uk if you do not wish to create an account but would still like to share your experiences.

[Get involved](#)



Join a lung cancer clinical trial advisory group

Researchers at the Cancer Research UK Imperial Centre are looking for individuals with personal experience (as a patient or carer or family member) of advanced non-small cell lung cancer to advise on a new clinical trial looking at treatment for newly diagnosed lung cancer.

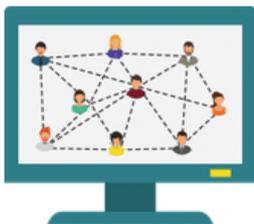
As an advisory group member, you will be involved in advising on all aspects of the trial. Including supporting the research team to ensure that the design, management and undertaking of this clinical trial is relevant, acceptable and appropriate to those participating in the trial as well as wider patients, relatives and carers.

The role involves approximately 8 x half-day meetings across the 5.5 years of the trial.

This is a paid opportunity, with reimbursement provided for time involved as well as other relevant expenses.

Find out more and apply via the button below.

[Find out more & apply](#)



Join a paid online discussion session on Non-Alcoholic Fatty Liver Disease (NAFLD) Research

Researchers at Imperial College, London would like to invite individuals with **lived experience of NAFLD (as a patient, carer or family member)** to join an online patient and public discussion on Monday 6th September 2021 from 5 – 6.30pm via **zoom** to hear about and share your views on NAFLD research. The researchers will be discussing three areas of research:

- Bariatric surgery and NAFLD
- The use of artificial intelligence for liver biopsies
- NAFLD and postmenopausal women

During the online session attendees will be given:

- an introduction to NAFLD research undertaken at Imperial College London
- an opportunity to ask any questions
- an opportunity to share your views on one of three research areas above in smaller group discussions to help shape and develop this area of research.

Payment:

We are offering £42.50 to take part in the 1.5-hour session via Zoom. This payment is based on the National Institute for Health Research payment policy for public involvement and includes a £5 contribution towards data/internet costs that may be used to access Zoom.

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[Sign-up to the session](#)



Help inform stroke research at Imperial College Healthcare NHS Trust

Researchers at Imperial College Healthcare NHS Trust are designing a trial to look at performing thrombectomies (a procedure which removes the clot causing an ischaemic stroke) in patients who are not currently eligible for the procedure.

To help design their research project, they would like to invite individuals with personal experience of stroke (as a patient, family member or carer) to join an online workshop on Thursday 2nd September from 17.30 - 18.15 via zoom.

The purpose of the workshop will be to hear more about the proposed research and to share your views. No scientific or medical background is required!

To find out more and register your interest please contact Dr Eleanor Taylor via eleanor.taylor19@nhs.net or 0203 313 0147



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](#)



Join the Imperial College, London Young Persons' Advisory Network

Are you aged between 17 - 25 years old, or know someone who is?

The Young Persons' Advisory Network (YPAN) has been set up as a collaboration between the Imperial Patient Experience Research Centre (PERC), the [Imperial Institute of Global Health Innovation](#) and the [Imperial Clinical Trials Unit](#).

The YPAN is open to all individuals aged between 17 - 25 years old, who are interested in influencing, and learning more about health research which is relevant to young people.

[Find out more & sign up](#)

Upcoming events



The role of genetics in determining cancer risk

Tue 14 Sept (13.00 - 14.00 BST)

In this online seminar presented by the Imperial College Academic Health Science Centre, two experts will talk about their work investigating role of genetic factors in cancer, the interplay of genetics with other risk factors and how this research can be used in cancer screening.

Register for free [here](#)

What's in the air you breathe?

Thu 19th August (12.30 - 13.15)

Meet the artist and air quality scientist empowering London's residents to stand up for cleaner air.

Find out more and register for free [here](#)

Save the date: Great Exhibition Road Festival 2021

9 - 15th October 2021

The Great Exhibition Road Festival will return to South Kensington and online from 9-15 October 2021. Further details, including the Festival's programme will be released shortly.

Keep an eye on the [festival website](#) for further details.

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 news & updates



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](#)

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:



[Involving Year One students to help shape research into physical activity and child health](#)

Dr Bina Ram, Child Health Unit, Department of Primary Care and Public Health, Imperial College, London

[Involving women to design and develop research into early-onset pre-eclampsia](#)

Olive Adams, Patient and Public Involvement (PPI) Midwife, Women's Health Research Centre at Imperial College London.



Take part in NIHR's Public Involvement Feedback Survey for 2020-21

This National Institute for Health Research's (NIHR) Public Involvement Feedback Survey is now open to patients, carers, service users or members of the public involved in NIHR work and/or shaping its research over the past 18 months (since January 2020). This may include:

- as a member of a local or national advisory group
- reviewing research applications
- sitting on an NIHR funding committee
- identifying research priorities
- being a co-applicant on a NIHR funded research study
- helping design, deliver and disseminate a research project
- as a Public Research Champion
- at one of our centres, facilities, or programmes

The information collected through the survey will be used to inform policy and the future public involvement work within NIHR, and help prioritise areas for improvement.

The survey closes on 22nd August 2021. Click the button below to access the survey.

[Take the survey](#)

Research News



Research in Focus: Responding to Covid-19 through research

Research studies have been more important than ever during the Covid-19 pandemic. Improving our understanding of the disease and finding better treatment options for patients have been top priorities for scientists around the world. Imperial College Healthcare has been at the forefront of many of these national and international studies. In the first of a new series of videos hear how Imperial College Healthcare NHS Trust staff have been transforming medical science.

[Watch the video here](#)

Contact us:

publicinvolvement@imperial.ac.uk

Our mailing address is:

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