

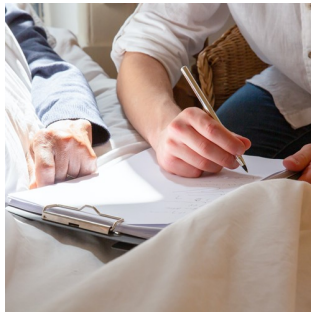
Patient Experience Research Centre

Public Involvement Newsletter

Welcome to the June 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 from the first half of 2021.

Involvement and engagement opportunities



Do you live with frailty and/or long-term conditions or support someone who does?

Researchers at the Imperial Patient Experience Research Centre are looking to involve people with the above lived experience to guide new research aiming to co-create information materials that will help people living with frailty and long-term conditions in making decisions about how they would want to be cared for if they became unwell.

The researchers are particularly looking for individuals who live or receive care in North West London who are willing to provide feedback on the development of the research, the ways of carrying out the project and how findings can be put into practice.

You would become a member of the project advisory group which would meet 5 times (online) over the next 18 months.

Find out more about the opportunity and express your interest via the link below.

Deadline to apply is 23rd June 2021.

[Click here](#)



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 following link.

[Click here](#)



Share your experience of stroke to help inform research into apraxia after stroke

Have you had a stroke? Do you find it difficult to complete everyday tasks such as brushing your teeth, tying a shoelace or making a cup of tea? Difficulty with the order of the steps in skilled tasks such as these is called apraxia, a neurological condition which may be unrelated to weakness caused by stroke.

Neurologists at Imperial College NHS Trust are planning a research project to help identify apraxia after stroke and to understand the effects of therapy for apraxia.

They are inviting people with experience of stroke (as a patient or carer) to be involved in a 1 hour online focus group in late June/early July to help shape this research project.

To find out more and apply please click the link below.

Deadline for applications is 25th June 2021.

[Click here](#)



Help shape research into COPD and swallowing

Researchers at Imperial College NHS Trust are developing a new research study aiming to understand whether swallowing is impaired during an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD).

They are looking for individuals living with COPD to take place in an online session to share views on the research including the research question and design to ensure the research is acceptable for people living with COPD.

The meeting is taking place next Wednesday 23rd June, 13.00 - 14.00 BST via Zoom.

To get involved and for further information please contact Lee Bolton via leebolton@nhs.net



Help shape research into treatment for venous disease

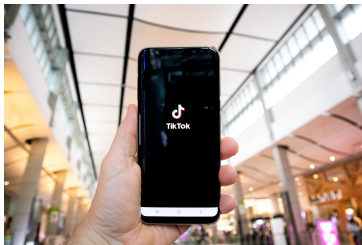
Vascular surgery researchers at Imperial College London are developing a new project to explore the best treatments for people with narrowed or blocked leg veins, known as 'venous disease'.

The research will compare the use of stents (tubes that expand once being placed into a vein), compared to tight elastic stockings and blood-thinning medicines to understand the best treatment for people with narrowed or blocked leg veins.

The researchers are keen to ensure their research is acceptable and appropriate and are therefore asking for individuals with lived experience of venous disease to share their views on the study by completing a brief survey (approximately 5 - 10 minutes).

You can access the survey via the link below.

[Click here](#)



Get involved in the SCAMP Study

[SCAMP \(Study of Cognition, Adolescents and Mobile Phones\)](#) is a major study within the School of Public Health at Imperial College London, We have been following secondary school pupils across London since they were in Year 7 (ages 11-12) through to early adulthood to look at whether the use of mobile phone use has an impact on affect young people's mental and physical health.

We have already been following SCAMP participants for the past 5 years since they were 11. We have recently been awarded an exciting multi-million pound grant from the UK Medical Research Council (MRC) to continue to study SCAMP pupils for a further 5 years and investigate mental health during the transition from adolescence to young adulthood.

We are keen to widen our network and are inviting members of the public (particularly parents & teachers) who are interested in hearing more about this research and/or helping us share research findings within their own community & schools to join our network. We also foresee a number of opportunities for involvement and engagement within the study which we will share amongst our SCAMP network.

To find out more and get involved please email the SCAMP team at scamp@imperial.ac.uk with the subject title "SCAMP Network Interest".



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 link below.

[Click here](#)

Upcoming events



Sickle Cell Disease Workshop:

Sat 19th June (14.00 - 15.30 BST)

An interactive workshop open to family, friends, patients and medical students with experience or interest of Sickle Cell Disease. The workshop will be held on World Sickle Cell Day and will bring together patients, family, friends, psychologists and doctors to explore the impact of Sickle Cell Disease and coping with this long-term illness.

To sign-up email: invisiblewarrior.scd@imperial.ac.uk

What's next for psychedelic science?

Wed 23 June (17.00 - 18.00 BST)

This online event will celebrate the achievements of the pioneering Imperial College London Centre for Psychedelic Research and will include discussion on the ambitions for the Centre and the future of psychedelic science in treating conditions such as depression, anorexia and chronic pain. The presentations will be followed by a live !&A in which you will be able to pose your questions to leading researchers in this field.

Sign up via Eventbrite: [Click here](#)

Imaging Technology to Fight Drug Resistance Webinar:

Thu 24th June (15.00 - 16.30 BST)

Hear how researchers at Imperial College London are developing microscopes that will be used in cancer research to study 3D cells and answer questions related to why cancer patients become resistance to medication and how we can develop better drugs.

Sign up via Eventbrite: [Click here](#)

Prenatal and early life influences on child health: Thu 15th July (13.00 - 14.00 BST)

Environmental factors and nutrition during pregnancy and the early years of a child's life can have significant effects on health, sometimes extending into late childhood and even adult life. In this online seminar hear two experts from Imperial College London discuss their research in this area.

Open to all. **Sign up via Eventbrite:** [Click here](#)

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](#)

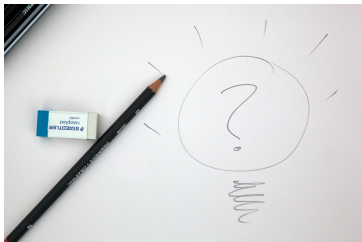
Public involvement news & updates



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.

You can find out more information about the course and details on how to access it [here](#).



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:

[Using Twitter to raise public awareness of health data use & sharing:](#)

[Our reflections of being involved in a Data Saves Lives' Tweet Chat](#)

John Norton, Public Contributor & Halle Johnson, Public Involvement Officer

[Four reasons why my placement at the Patient Experience Research Centre \(PERC\) has been beneficial for my PhD](#)

Carmel McGrath, PhD Student, Southampton Biomedical Research Centre

[Involving parents to inform research into pre-school wheeze:](#)

Dr Hanna Creese, Research Associate, Imperial Child Health Unit

[Involving teenagers in research about the environment and mental](#)

[health:](#) Rhiannon Thompson, PhD student, Imperial Department of Epidemiology and Biostatistics

[Designing follow-up care for stroke with those who know it best:](#)

Jennifer Crow, Clinical Specialist Occupational Therapist in Stroke,
Charing Cross Hospital

[You and your hormones: engaging and educating the public about](#)

[endocrinology](#): Dr Ali Abbara, Dr Chioma Izzi-Engbeaya, Department of
Metabolism, Digestion and Reproduction

Research News

Meet the scientists behind the REACT study



REACT (REal-time Assessment of Community Transmission) is a series of studies that are using home testing to improve our understanding of how the COVID-19 pandemic is progressing across England. This major research programme was commissioned by the Department of Health and Social Care (DHSC) and is being carried out by Imperial College London in partnership with Ipsos MORI and Imperial College Healthcare NHS Trust.

The programme of research has now been running for over a year, with two million tests completed by individuals across England.

In this feature article the scientists behind the programme tell their stories of how it all unfolded, what they've learned, and their hopes for REACT's legacy on science and beyond.

[Read the story here](#)

NIHR | National Institute
for Health Research

New Online Training Course: Understanding the research behind the COVID-19 pandemic

Developed by the NIHR Clinical Research Network and the University of Leeds this course aims to uncover the UK's critical health research response in the NHS - which discovered new vaccines and proven treatments in response to the COVID-19 global healthcare crisis.

The training aims to enable you to:

- Understand how COVID-19 vaccines and treatments have been developed at speed whilst not compromising the safety of research participants.
- Learn about research processes and how research is regulated and approved.
- Hear about the experiences of patients who have been involved in clinical trials and communicate clearly to those who are interested in taking part in research.

- Reflect on the concerns of patients about research and gain evidence-based information to support conversations about COVID-19 vaccines and treatments.
- Reflect on the impact of the pandemic on the future of research.

Find out more about the course & sign up on the Future Learn Website. [Click here](#)

Contact us:

publicinvolvement@imperial.ac.uk

Our mailing address is:

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