

Patient Experience Research Centre

Public Involvement Newsletter

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

This will be our last newsletter for this year, and we wanted to take this opportunity to reflect on the activity undertaken over the last year and look towards 2022.

Over the past months we have been undertaking a series of public involvement activities, including online discussions and surveys, to inform the National Institute for Health Research (NIHR) Imperial Biomedical Research Centre re-application competition.

We have also continued to extend our COVID-19 research, with the REACT (REal-time Assessment of Community Transmission) study, one of the world's largest COVID-19 home monitoring studies, reaching over 2 million participants. This project has now also been extended to explore ongoing symptoms after COVID-19 in the REACT Long COVID study (REACT-LC).

You can find out more about our COVID-19 research and public involvement activities in the news and updates section of the newsletter.

We would also like to take this opportunity to thank everyone who took the time to be involved in these recent activities and say a big thank you for all your continued support and involvement this year. We wish you all a wonderful, safe and restful festive period, and are looking forward to working with you in 2022!

Involvement and engagement opportunities



Share your views in an online workshop to help improve uptake of Lung Health Checks in London

The NHS Lung Health Check is a new service that is offered in some parts of England. It aims to help diagnose lung cancer at an earlier stage when treatment may be more successful. Lung Health Checks are now available in West London for patients at participating GPs across Hillingdon, Hammersmith & Fulham, and Sutton, however, to date, uptake of the checks has been low.

Imperial College, London and the Royal Marsden are running two workshops in early-mid December 2021 to further understand why eligible people are choosing to not have their lung health checks and to explore and co-develop new ways in which we can encourage participation.

Who can get involved?

Members of the public who:

- Live or receive care in London
- are aged 55-75 years old
- are current or previous smokers
- have **not** attended their Lung Health Check (following invitation) or **are not interested in** participating in a Lung Health Check (if they were available in your area).

When and where?

The workshops will take place online and you will be asked to provide your availability for the following dates/times when you register your interest:

- December 8th (10.00 - 11.30)
- December 9th (14.00 - 15.30)
- December 15th (13.00 - 14.30)

Payment:

Attendees will be offered up to a total of £42.50 for participating in line with NIHR policy of £25 per hour + £5 remote working fee for each workshop in line with NIHR payment rates for public contributors.

Find out more and register your interest via the link below by **5pm on the 1st December 2021**.

[Get involved](#)



Join an online public involvement discussion on pregnancy care following bariatric surgery

Researchers at Imperial College, London are inviting women (and/or their partners) who have experience of pregnancy following bariatric surgery (including gastric bypass and sleeve gastrectomy surgeries) to be involved in an online discussion to help shape new research in this area.

During the online meeting you will:

- be provided with an introduction to the research proposal and wider research area
- have the opportunity to ask any questions
- be asked to share your experiences of pregnancy following bariatric surgery in a small group discussion.

When and what time:

The meeting will take place online (via zoom) and will run for 1 hour.

You will be asked to provide your availability for the below dates within the expression of interest form and we will go with the date/time which works for the majority.

Tuesday 7th or Thursday 9th December: 5.15 - 6.15pm

Payment:

Those involved will be offered up to a total of £30.00 for participating in line with NIHR policy of £25 per hour + £5 remote working fee for each workshop in line with [NIHR payment rates for public contributors](#).

Find out more and register your interest via the link below by **midday on Wednesday the 1st December 2021**.

[Get involved](#)



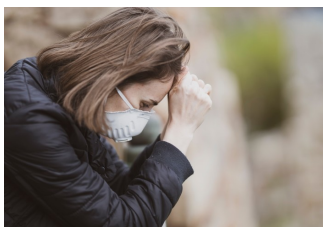
Join the Health Data Research UK Public Advisory Board

Health Data Research UK (HDR UK) is the national institute for health data science. Their public advisory board has been in place since January 2019 and they are now seeking to appoint 9 to 12 new members to this.

The purpose of the board is to provide strategic advice to the organisation. Members will be asked to use their unique patient and public perspectives and insights on the safe and secure access and use of health data in research for public benefit to shape and influence our work.

You can find out more about the role and how to express your interest via the button below.

[Find out more](#)



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 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 VOICE



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

Upcoming events



Webinar: Antimicrobial Resistance and Healthcare Associated Infections Research Thursday 2nd December 2021 (18.00 - 19.30 GMT)

This free webinar is aimed at members of the public with an interest in public health research. The session will bring together researchers from the NIHR Health Protection Research Unit in Healthcare Associated Infection (HCAI) and Antimicrobial Resistance (AMR) to share their planned research and answer questions from the public on this research area.

[Sign up via Eventbrite](#)

Webinar: How healthcare data and artificial intelligence can improve care Tuesday 14th December 2021 (12.00 - 13.00 GMT)

Healthcare data and artificial intelligence (AI) are helping clinicians make better treatment decisions and improve the quality and safety of healthcare delivery. In this seminar two experts (Erik Mayer and Dr Céire Costelloe) will talk about their work on using healthcare data for direct patient benefit.

[Sign up via Eventbrite](#)

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



Public involvement insight reports launched

To inform the NIHR Imperial Biomedical Research Centre (BRC) reapplication for 2022 to 2027, the Patient Experience Research Centre facilitated a programme of public involvement activity from November 2020 to September 2021.

The public involvement activity included online discussion sessions, online surveys, and specific activities with community members across North West London (NWL) around the following topics:

- Digital Health
- Metabolic disease (e.g. diabetes)
- Social, Genetic and Environmental Determinants of Health
- Weight and fertility
- Non-Alcoholic Fatty Liver Disease
- Molecular Phenomics (the analysis of biological fluids or tissue samples to improve disease diagnosis)
- Respiratory Medicine
- Brain Sciences
- Involving children, young people and families in our research
- Multiple Long-Term Conditions
- Cardiovascular
- Digestive Diseases

The purpose of each of the activities was to understand the priorities and unmet needs of our local NWL community to further inform the development of the Biomedical Research Centre's research programme.

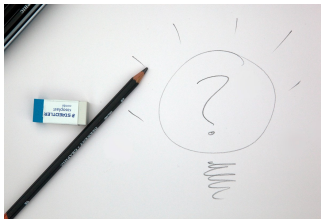
The insight reports for each of the public involvement activities which summarise the activities and outputs are now available on our [website](#).

Insight reports summarising key points from the activities were made available to Theme leads, the BRC Executive and the public who took part in the involvement activities. These reports are summarised in the [full report](#) and were used to shape the BRC application and have specifically informed the Patient and Public Involvement, Engagement and Participation section, including proposed public involvement in governance and resourcing.

We would like to thank all those members of the public who gave their time and thoughtful insights through these activities, and the researchers who engaged enthusiastically in the process.

[Go the insight reports](#)

New paper: Co-design of Guidance for Patient and Public Involvement in Psychedelic Research



Public involvement is increasingly considered a prerequisite for high-quality research with the potential to improve research relevance, quality, and impact. There are now numerous guidelines, frameworks, and tools for supporting public involvement in research, however, these do not account for the unique challenges faced in psychedelic research.

In a new paper in [Frontiers of Psychiatry](#), the Centre for Psychedelic Research worked with Sandra Jayacodi (Lay chair of the Imperial Biomedical Research Centre Public Advisory Panel) to co-design new guidance to build, evaluate and improve public involvement in psychedelic research.

A steering group was formed to design and run a co-design workshop alongside public collaborators. Insights from this workshop were analysed and refined into a comprehensive and readily usable guide for planning PPI specific to the field of psychedelic research.

Find out more about the activity and the findings in the paper via the button below

[Read the paper](#)



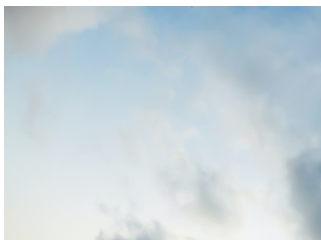
Catch up on the activities from Antimicrobial Resistance Awareness Week

Antimicrobial Resistance (AMR) occurs when bacteria, viruses, fungi and parasites change over time and no longer respond to medicines making infections harder to treat and increasing the risk of disease spread, severe illness and death.

As part of Antimicrobial Resistance Awareness Week, the NIHR Health Protection Research Unit in Healthcare Associated Infection and Antimicrobial Resistance at Imperial College London has launched a new public engagement game called Dicing with Death. The game which aims to explain what antimicrobial resistance is to members of the public and what they can do to help prevent it. You can find out more and play the game via the below link.

You can also find out more about Antimicrobial Resistance at the team's [upcoming public event](#) and watch [their recent video](#) made by children of the centre's staff explaining the importance of antimicrobials in underpinning modern medicine, in an amusing and accessible way. The purpose of the video is to make people think broadly about how important antimicrobials are to their wellbeing.

[Find out more](#)



Job Vacancy: Well Home Local Community Engagement Coordinator

Are you passionate about local engagement and experienced in delivering projects with diverse local communities? If so, an exciting new opportunity has arisen to join Imperial College, London as the Local Engagement Coordinator for our new Well Home indoor air quality research project.

WellHome is a pioneering project to investigate the quality of air both inside and outside the home. Working with 100 households from across West London, they will be looking at the impact of air quality on our health and delivering a programme of outreach and public engagement.

The Local Community Engagement Coordinator is crucial to the success of the project and will be responsible for engagement with local residents and stakeholders, developing local partnerships and ensure the project is developed in collaboration with our local

communities.

Find out more about the role via the button below.

Deadline to apply is **9th December 2021**.

[Find out more](#)



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



Recent findings from REACT: COVID-19 vaccination cuts infection risk by half in school-aged children

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.

Results from swab tests taken at home by over 100,000 people in England between 19 October 2021 and 5 November 2021 showed that 1.57% of people were infected, or 1 in 64.

School-aged children had the highest infection prevalence at 5.21% for 13-17-year-olds, and 4.95% for those aged 5-12, or around 1 in 20. However, the study also found that vaccination was helping to reduce virus spread among children. Those aged 12-17 who had received a single Pfizer/BioNTech dose had around a 56% lower risk of infection compared to unvaccinated children. The risk was even lower for symptomatic infection, at around 68%.

The study also looked at the effectiveness of booster doses at preventing infection, finding that the risk of infection was around three times lower in those who had received a third dose, compared to those who had received two. For those who were aged 50 and above, having a third dose reduced the infection risk by around half compared to two doses.

[Read the full news article](#)

Keep up to date with our COVID-19 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 \(REal-time Assessment of Community Transmission\) 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 which signing up to VOICE. A newly launched platform which 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 platform to share opportunities to get involved or take part in their projects, as well as the latest news and events.

Contact us:
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