Imperial College London Young Person's Advisory Network **Newsletter**

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.

Welcome to the December issue of the Imperial College, London Young Persons' Advisory Network

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

Involvement and engagement opportunities

Health Data Research UK (HDR UK) is the national institute for health data science. Their public advisory board has been in place since

Advisory Board



in 2022!

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

Join the Health Data Research UK Public

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. The deadline to apply is 5pm on Sunday 19 December 2021 Find out more

Become a Student Lifestyle Tracking Cohort

Study Young Advisor

might be associated with any change.

at least 2 per year.

What support will I receive?

questions

How to apply?

button below.

services

on the hub.

years old) to help: shape our survey to medical students, making sure the questions are sensitive, relevant and accessible to medical

The research team are looking for 2 young people (aged 18 – 25

The Student Lifestyle Tracking cohort study (SLT) aims to assess how lifestyle behaviours (such as sleep, physical activity and diet) of medical students vary over the course of their study and what factors

 advise on strategies for recruitment With the analysis and interpretation of survey findings co-produce outputs/strategies to improve health behaviours for medical students

- provide support and advice across the project as needed What is involved?
 - There will be a 1 hour meeting every 8-12 weeks. You are not

required to attend all meetings, but you are expected to attend

- The advisory role requires a minimum commitment of 2 years, with the opportunity to stay on for the full 6-year research
- involvement • Appropriate training to undertake the role (where needed)

• To have a key contact within the team to answer any

• Receive up to £150 per year as reimbursement for your

• To be kept updated on the project and be given regular feedback on the changes made as a result of the young advisors' input

Please express your interest by completing a short online form via the

The deadline to apply is 31st December 2021 and applicants will be contacted in early January 2022 regarding the outcome of their application.

Get involved

Contribute to the 11 to 25 Online Resource **Hub at Imperial College Healthcare NHS** Trust

The 11 to 25 Hub is a new online resource being developed by clinicians at Imperial College Healthcare NHS Trust to support, inform and educate young people transitioning from children's to adults'

As part of the development of this hub the team are looking for short stories or voice notes sharing experiences of healthcare transition. These will be used as learning opportunities and short case studies

Your help defining Long COVID

Stories are being captured on an ongoing basis.

To find out more please contact Chris and Claudia

at Imperial.11to25hub@nhs.net

When carrying out research to understand (and define) a new condition such as Long COVID, it's

For the last few months we have been collecting your experiences of long COVID symptoms as part of our Defining Long COVID challenge on the VOICE-Global online platform and this is what

peace silence

sleeping problem fit

· longer loss companion Louder hours

better Wake Extreme noises

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.

back

hold memory

pain hangover level sudden cramp

random

recall energy issues

define the symptoms and/or effects of COVID-19.

share your experiences.

ling children and young people ag 10-20 with learning disability and epilepsy

Imperial College London

painful

headache

daily

sensation

months heart

respondents have told us in your own words so far: Forgetting cant breathing try think body trying severe hard muscle exhaustion

different other unable

work physical

fast exertional

head nausea

noise heavy self

shoulder throat eyes

nothing hands lie weight

full walk burning We are continuing to invite responses as part of this challenge, to help understand the varied experience of Long COVID as part of the REACT Long COVID research project. Your experiences will not only help us improve the way we conduct our REACT Long COVID research, but we also

Get involved

increased patchy

10-20 with epilepsy and learning disability to be interviewed (you can have a parent or carer present) Your feedback will: Shape our research questions

Upcoming events

Virtually via Zoom Live Events

Including:

To register go <u>here</u>

such as improving hygiene or developing diagnostic tools for use in remote areas. Each year, the Institute then hosts a Dragon's Den-style event to find the winner where the finalists for the competition are invited to pitch their idea to our judges. You can find out more on their website and submit your idea

Further information 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 Pint of Science 2022

Celebrate science and the arts at home and in person at South Kensington next Summer.

• DEBATE – "This house believes conventional immunosuppressants have failed our patients and we should be encouraging the use of targeted biologics from the time of diagnosis"

6th Adolescent Rheumatology Symposium (Tuesday 25th January 2022 09:00am - 5pm)

· Nutrition and metabolism in adolescent rheumatology.

• Machine learning approaches in juvenile-rheumatic diseases

Save the date: Great Exhibition Road Festival (17-19th June 2022)

Public involvement and engagement news & updates Public involvement insight reports launched

2020 to September 2021.

Digital Health

· Weight and fertility

· Respiratory Medicine

· Brain Sciences

Cardiovascular

governance and resourcing.

· Digestive Diseases



New Paper: Adolescents' thoughts and feelings about the local and global environment: a qualitative interview 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.

of public involvement and co-production in health research as well as discussing in more detail the role of public involvement across the

Find out more

Read the full news article

new tiredness smell cognitive Tinnitus seek constant arms headaches pains migraine experience sensations stop t deep understand worse sleep hope this challenge will spark a bigger, more collaborative campaign to visualise, understand and To get involved you can share what your symptoms feel like in your own word (or pictures), read what others have said and chose other responses which resonate most to you. 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 Calling young people aged 10-20 with epilepsy and learning disability Researchers at Imperial College are planning to measure the health of children and young people with epilepsy and learning disability. They are looking for young people aged Inform the way we do our research Help to circulate our findings You will be paid for your time. If you are interested, please contact Dr Rakhee Shah for more information at rakhee.shah@imperial.ac.uk. Take part in the Imperial Institute for Global **Health's Innovation Prize** Formerly known as the Student Challenges Competition, IGHI's Health Innovation Prize offers UK university students the opportunity to showcase their research and to win £10,000 towards funding their global health project. Applications are open to all UK-based university students. Projects can cover any aspect of global health innovation, from the 10th January 2022. Find out more

The Pint of Science festival aims to deliver interesting and relevant talks on the latest science research in an accessible format to the public – across bars, pubs, cafes, and other public spaces. We want to provide a platform which allows people to discuss research with the people who carry it out and no prior knowledge of the subject is

the Pint of Science UK here.

While the festival has been virtual for the past two years, they are

If you would like to be one of the Imperial College London volunteers sign up here for 2022. To hear more about the upcoming events follow

hoping to be in person for their next run 9-11 May 2022.

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

The public involvement activity included online discussion sessions, online surveys, and specific activities with community members across

• Social, Genetic and Environmental Determinants of Health

• Molecular Phenomics (the analysis of biological fluids or tissue

• Involving children, young people and families in our research

The purpose of each of the activities was to understand the priorities and

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 $\underline{\text{full}}$ report and were used to shape the BRC application and have specifically

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

informed the Patient and Public Involvement, Engagement and Participation section, including proposed public involvement in

unmet needs of our local NWL community to further inform the

North West London (NWL) around the following topics:

• Metabolic disease (e.g. diabetes)

• Non-Alcoholic Fatty Liver Disease

• Multiple Long-Term Conditions

samples to improve disease diagnosis)



Go the insight reports

who engaged enthusiastically in the process.

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

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

Despite a recent increase in engagement with environmental issues among young people, their impact upon adolescent mental health and wellbeing is not yet fully understood. Therefore, this study aimed to explore adolescents' thoughts and feelings about current environmental issues. This study formed its own Young People's Advisory Group (YPAG) of twelve adolescents recruited using professional and personal networks. They were involved in the initial project planning, and formation of the information sheet, consent form and recruitment adverts. Two members went on to become co-researchers for the remainder of the research cycle. To read more about the results please click the button below Read the paper Want to learn more about public involvement in research? Sign up to our online course on $\underline{\mbox{\bf Public Involvement in Research}}$ 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

research cycle.

Results from swab tests taken at home by over 100,000 people in England between 19 October 2021 and 5

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

To keep up to date with our ongoing COVID-19 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 • By signing up to VOICE, you will also have access to our Long COVID Research Involvement Hub (make take part in their projects, as well as the latest news and events.

Research News

November 2021 showed that 1.57% of people were infected, or 1 in 64.

Voice

well as upcoming events relating to health and social care. button below Join VOICE

Contact us: 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 Young Persons' advisory Network mailing list. To unsubscribe from these updates (or edit your preferences), please reply to this email with 'UNSUBSCRIBE' (or 'EDIT') in the subject

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. You will find opportunities for involvement, engagement and participation as To keep updated with the latest VOICE opportunities and help to influence and inform our research, sign up today via the