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## ARC West Midlands & Midlands PSRC News Blog



# Implementing Decision Aids in Routine Clinical Pathways

*Richard Lilford, ARC WM Director, PSRC Midlands Co-Director*

*& Annie Lester, Consultant Midwife UHBFT*

**W**e have often discussed supporting patients who have to make various preference-based decisions. First, we discussed the general philosophy of non-directive counselling,[1] then we discussed information overload and the information paradox.[2] Last month we reviewed literature on the design of decision aids.[3]

This article is concerned with integrating decision aids in routine clinical pathways. We major on this project because preference-based healthcare is a key component of our NIHR Midlands Patient Safety Research Collaboration (PSRC) and our NIHR Applied Research Collaboration (ARC) West Midlands.

It is first worth making a distinction between patient leaflets and decision aids. An information leaflet delivers information passively, while a decision aid is structured to help individuals actively make choices based on that information.

A very thorough, review from the International Patient Decision Aid Standards (IPDAS) collaboration, provides essential reading.[4] It is co-authored by Angela Coulter, who is a valued advisor to our PSRC. The authors consider barriers and facilitators in implementing decision aids in routine clinical settings. The review excludes all studies carried out in controlled settings or as part of clinical trials; the focus is very much on the real world.

The authors start by pointing out that decision aids are widely studied, but very seldom implemented in routine practice. This is despite almost uniform evidence that they are beneficial,

as stated in previous articles in this series.[1-3, 5] The review summarises evidence from 23 studies. The information is arranged, not surprisingly, according to the five Consolidated Framework for Implementation Research (CFIR) domains (with which News Blog readers will be familiar!).

In our work on uptake of surgical trial results, we find that intervention characteristics and the perceived strength of evidence dominate as barriers to uptake. However, in the case of decision aids, this is not a major factor, save that the simpler the decision aid, the more likely it is to be used. One of the emerging themes from the series is that it is necessary in the design of decision aids to compromise and not allow the ideal to be the enemy of the good. For example, time constraints and avoidance of information overload are in contention with full disclosure of all elements. Decision aids control the consistency of information delivered, and may go some way in supporting the manner in which the information is communicated, but cannot stand on their own without training around how they should be implemented.

The 'inner setting' emerges as a very important facilitator, since the attitude of staff makes a big difference to implementation. In particular, implementation is fostered if there is pervasive support for informed decision-making across the hierarchy. Dedicated clinical leadership was crucially important, as was developing and supporting skills in the use of decision support. This point reminded me of an article on education for cardiologists reported in an earlier News Blog.[6]

Another strong facilitator is advising patients ahead of time that they will be introduced to decision support and making patients feel that they all supported in autonomous decision-making.

A systematic review looks at the provision of decision coaching when decision aids are used. [7] Decision coaching relates to the advice and support that a clinician gives to a patient alongside the use of a decision aid. A scoping review of this topic did not find much evidence to support its use.[8] However, the evidence is not strong either way. It seems a sensible thing to do and is supported by the International Patient Decision Aid Standards.

The theme that emerges from these studies is that decision-aids need to be carefully integrated into the system to make sure that they are readily available. The below Table lists issues with decision support and methods through which the health system can mitigate these issues.

The general point that the performance of decision aids depends on how they are integrated into the broader health system was reinforced by a recent JAMA article on performance of early warning scores for clinical deterioration.[9] The point is well made that how well the score works is not just a function of sensitivity and specificity, but how well it “drives work-flow” within the system.

Issue	Mitigation
Decision-aids are not available when needed.	Incorporate in electronic record, so they are ‘prescribable’ and available over internet.
Information overload precedes delivery of all relevant information.	Trim information at first visit. Ascertain appetite for detail. Offer further reading (including leaflet).
Time constraints.	Layer information, as per above – prescribe leaflet, web page, etc. that can be reviewed in own time.
Differences in language health literacy.	Arrange interpretation – refer to language-specific leaflets.
Co-ordination / consistency / tailoring schedule of appointments and layering of information to suit decision-makers.	Staff education / encourage patient feedback.

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1. Lilford RJ. Informing and Facilitating Choice in Maternity Care: What Do We Know & Where Are the Research Gaps? *NIHR ARC West Midlands News Blog*. 30 June 2023; **5(6)**:3-6.
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5. Lilford RJ. Do Quality-Adjusted Life Years Overestimate the Benefit of Life-Saving Treatments? *NIHR ARC West Midlands News Blog*. 3 December 2021; **3(12)**: 6-7.
6. Lilford RJ. One-to-One Coaching Improves Cardiologists' Communication Style. *NIHR ARC West Midlands News Blog*. 10 May 2023; **5(4)**: 6.
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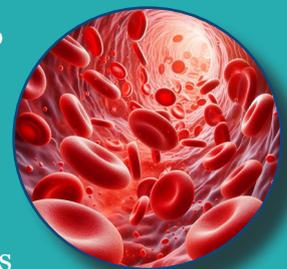
## Quiz

What is Haemophilia B or Factor IX deficiency also known as?

email your answer to: [arcwm@contacts.bham.ac.uk](mailto:arcwm@contacts.bham.ac.uk)

*Answer to previous quiz:* Dracunculiasis (Guinea-worm disease) is spread via copepods or 'water fleas' that live in stagnant surface water, and are often infected with Guinea worm larvae.

Congratulations to those who answered correctly.





# The Multidisciplinary Team for Cancer Care: More Harm Than Good?

Richard Lilford, ARC WM Director; Midlands PSRC Co-Director

People who receive a diagnosis of cancer are highly stressed, and so too are their families. The pathway to the diagnosis of cancer is characterised by a particular form of psychological stress: the stress of waiting. Much of this is simply unavoidable, involving referral, appointment, investigation, biopsy, and planning treatment.

It is in the planning of treatment that the agony of waiting can be reduced. This could be accomplished by a simple stroke of the pen – get rid of the routine insistence for tumour boards or MDT (a Multi-Disciplinary Team of health professionals who work together to plan treatment best suited for the patient).

The genesis of the MDT seems to lie in the idea that a single clinician cannot be trusted to set the patient off on the appropriate pathway. When I have asked specialists about this, they have sometimes replied that it will prevent rogue surgeons doing unnecessary operations, citing the notorious case of [Ian Paterson](#).

These are very weak arguments for routine referral to the MDT. First, the treatment for most patients is based on a standard protocol. Experienced physicians and surgeons are quite capable of following these guidelines; it is part of their job description. Second, the argument regarding rogue surgeons is simply not tenable;

why should tens of thousands of patients wait an extra couple of weeks, because of one notorious case?

A recent article in JAMA underscores the need to shorten the cancer pathway as much as can be safely achieved.[1] Moreover, there are good clinical grounds to shave time off the pathway. Much effort and work has gone into reducing the time between symptom and referral. This is because the evidence that delay reduces the chance of the cure, is extremely strong. Every month of waiting between diagnosis and surgery has been estimated to increase all-cause mortality by around 6-8%.[2]

I am not arguing that there should be no MDT Referrals, however. Of course, there are instances of complex cases that cannot be solved by guidelines alone. MDT referrals should be reserved for such cases.

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1. Gupta A, Johnson WV, Henderson NL, et al. [Patient, Caregiver, and Clinician Perspectives on the Time Burdens of Cancer Care. JAMA Netw Open. 2024; 7\(11\): e2447649.](#)
2. Hanna T P, King WD, Thibodeau S, et al. [Mortality due to cancer treatment delay: systematic review and meta-analysis. BMJ 2020; 371: m4087.](#)



# Sickness Rates in Post-COVID Britain

Richard Lilford, ARC WM Director; Midlands PSRC Co-Director

The alarming rise in long-term sickness rates recorded after the COVID-19 pandemic never struck me as convincing. I was unconvinced by reports of spiralling economic inactivity due to long-term illness. Apart from my inbuilt scepticism, the statistics did not make clinical sense – what kind of ‘sickness’ was causing people to stay off work. Cardiovascular disease? No, illness rates are declining. Cancer? No, rates are fairly stable. Bone and joint? No, most jobs in the economy can be done perfectly well, even if joints are hurting. This left mental health. There is a rise in teenage mental health problems, especially in girls. But this could not account for spiralling disability. Deteriorating mental health across the whole community does not seem a plausible cause of the increase in people registered as not working due to ill-health.

Although I did not buy the argument that a surge in ill-health was the cause of the problem, I did not have time to interrogate the data myself. Enter John Burn-Murdoch.[1] He found two problems with the illness epidemic hypothesis.

1. The rise is largely ‘illusory’. The original data that led to the scare is mis-leading. It is based on the Labour Force Survey, for which response rates are plummeting, leading to bias when comparing current with previous data. New and better data have become available from the UK Household Longitudinal Study, which has a more constant response rate. This finds that labour market participation is slightly *higher* than before the pandemic.

Meanwhile, the Resolution Foundation estimates similar levels of activity both sides of the pandemic.

2. Many unemployed people who would not have reported ill-health six years ago now report it because they are incentivised to do so. Three factors are at work here. First, health-related benefits are more generous than unemployment benefits. Second, a shift to online assessment as part of universal credit has made it easier to register a long-term illness. Third, it is hard to move back from long-term illness to ‘looking for work’ because simply applying for a job will invalidate the (more) ‘generous’ health benefits, thus ‘baking-in’ long-term sickness. Yet further evidence comes from the observation that long-term sickness rates in the working age population tend to track benefit generosity.

In short, the initial statistics told a ‘[damned lie](#)’, and the benefits system does the rest. Of course, none of this means that we should not try to reduce waiting lists and waiting times, and that doing so would not produce some productivity gains. However, the argument that we are experiencing a massive increase in long-term illness is weak.

## Reference:

1. Burn-Murdoch J. [What if the UK isn’t actually the sick man of Europe?](#) *Financial Times*. 6 December 2024.



# Increase in Colorectal Cancer in Young Adults

Peter Chilton, ARC WM Research Fellow

We have written previously on the worrying trend showing an increase in various cancers among young adults,[1] and a database study recently published in *Lancet Oncology* adds to the evidence-base.[2]

The authors used a global database (the WHO-International Agency for Research on Cancer Care Incidence in Five Continents Plus) to look at incidence data of colorectal cancer, separated into early-onset (diagnosed between 25-49 years old) and late-onset (50-74 years old).

Out of the 50 countries included in the database, the incidence rate of early-onset colorectal cancer has increased over the last ten years in 27 countries (remaining stable in the other 23), with the highest increases in New Zealand (~4.0% annual increase), Chile (~4.0%), Puerto Rico (~3.8%) and England (~3.6%). Although 13 of these countries have also seen an increase in incidence in older adults, these have mainly been at lower rates of increase than those seen in younger adults. In the remaining 14 countries, incidence rates in older adults are stable or have even decreased (including in England and Scotland).

Further analysis shows that in England and Scotland the incidence rate of early-onset colorectal cancer is increasing faster in women compared to men.

There is thus an urgent need to raise awareness

of the [signs and symptoms of colorectal cancer](#), for further research to identify what factors are influencing these increases, and the cost-effectiveness benefits of lowering the standard screening age for colorectal cancer (both the USA and Australia have recently lowered the eligible age from 50 to 45).

## Know the symptoms of bowel cancer



-  Bleeding from your bottom
-  Blood in your poo
-  A change in how often you poo, or regularly having diarrhoea or constipation
-  Losing weight but you're not sure why
-  Feeling very tired all the time but you're not sure why
-  A pain or lump in your tummy

If you have any of these symptoms, talk to your GP and ask about an at-home test.

## References:

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# Mastering the Basics of EDI in Clinical Education Research: Workshop Recap

*Valencia Kabeya, Postdoctoral Research Fellow, Midlands PSRC Maternity theme*

**O**n the 24th September, I had the privilege of leading a workshop titled **Mastering the Basics of EDI (Equality, Diversity, and Inclusion) in Clinical Education Research** at the *Mastering the Basics research training event* in Newcastle, organised by the Association for the Study of Medical Education (ASME). The workshop highlighted the significance of EDI in clinical education research, using the National Institute for Health and Care Research (NIHR)'s Research Inclusion Strategy 2022-2027 as a key framework for discussion.

The workshop aimed to help attendees understand the basics of EDI and its significance in fostering inclusive, high-quality clinical research. By the end of the session, participants were equipped with the tools necessary to evaluate the extent to which EDI principles are integrated into research, as well as how to apply these principles in their own work. A key focus was on the importance of understanding the NIHR People Framework, which is essential for successfully implementing the [NIHR's Research Inclusion Strategy](#). This framework encompasses various groups, including the NIHR's workforce, research workforce, advisory workforce, research participants, and the general public. Additional frameworks discussed included the [NIHR INCLUDE Ethnicity Framework](#), the [NIHR INCLUDE Impaired Capacity to Consent Framework](#), and the [NIHR INCLUDE Socioeconomic Disadvantage Framework](#), all of which aim to promote inclusivity in research.

There was a diverse group of attendees, including researchers, healthcare professionals, and clinicians from specialities like urology, gynaecology, endocrinology, and dentistry, as well as medical students. The feedback received from attendees was very positive. Many expressed how relevant and engaging they found the session and appreciated the practical insights into how to effectively embed EDI into research practices.

In later sessions, the importance of incorporating EDI into new research projects was emphasised, and principles taught and discussed on EDI in this workshop were highlighted as key resources. This workshop not only raised awareness of the importance of EDI but also gave practical guidance on how to include it in clinical education research.

The overall takeaway was that embedding EDI principles into clinical research from the beginning helps ensure that the research is both more representative and equitable in its outcomes. It leads to more inclusive and meaningful results. It was a rewarding experience, and I'm glad to have contributed to such an important conversation in clinical education research.

# Inferring Causality from Real-World Evidence

Christopher Hatton, Clinical PhD, Midlands PSRC Acute Care theme

**E**stablishing a causal association between an exposure or intervention and an outcome is a fundamental goal of research. Randomised controlled trials (RCTs) are widely regarded as the gold standard for establishing causality, as they ensure that known and unknown confounders are balanced between groups. Frequently, RCTs are impractical, unethical, or too costly and researchers turn to observational research to provide answers. However, inferring causality from observational research is more challenging. Target trial emulation is a framework for observational research that seeks to address some of these challenges.[1] The framework helps researchers to design observational studies in a way that replicates key elements of RCTs. When the stringent assumptions of target trial emulation are met the results are thought to be replicate those that would be identified in an RCT. An interesting paper published in JAMA explored whether this occurred in real life practice.[2]

The study emulated 30 completed RCTs using observational data derived from health care claims. These RCTs were chosen on the basis that all relevant data was likely to be available in the observational data and that confounding was balanced after propensity score matching. The original RCTs evaluated therapies in cardiovascular disease, bone disease, respiratory disease, and cancer. There was reasonable agreement between the results of the original RCTs and emulated trials; 72% had effect estimates and confidence intervals on the same side of the null. Agreement was even higher when closer emulation of the RCT was possible.

This was a thought-provoking study that explored an important methodological question. Whilst agreement between the results of RCTs and observational studies was reasonable, it was not perfect. The authors rightly highlight that discrepant results are also observed in RCT pairs with the same study design. This is likely to be secondary to a mixture of chance, bias, and differences in study design and statistical analysis. Ultimately, observational research is not a replacement for RCTs, but where RCTs are impractical high quality observational research can provide actionable insights for many health research questions.

## References:

1. Hernán MA, Wang W, Leaf DE. [Target trial emulation: a framework for causal inference from observational data.](#) *JAMA.* 2022;**328**(24):2446-7.
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# Testimonial on Analysis of Performance Reports by NHS Boards

*Samantha Riley, Director of Making Data Count*

“ I wanted to write and thank you for all of the research that you have undertaken related to the use of SPC charts in the NHS and the impact of the Making Data Count work that I have been leading.

Your initial paper published in 2016 ([Considering chance in quality and safety performance measures: an analysis of performance reports by boards in English NHS trusts](#)) has been a very important piece of evidence to demonstrate not only the value of using SPC charts, but also to highlight the lack of use and understanding of SPC charts in the NHS. This research paper has very much shaped the Making Data Count programme as it is today and I have tried to address each of the issues identified as barriers in the paper.

We have now undertaken 233 board development sessions and in addition have trained over 42,000 staff at different levels of seniority (clinical, managerial and support staff) – the majority of these virtually since the pandemic. We train analysts in both the theory behind SPC and the practicalities of how to create charts, plus we have made available a range of free products to enable SPC charts to be created locally. These range from easy to use Excel tools designed for frontline staff to several thousand lines of SQL script and Power BI templates which enable the creation of SPC charts at scale. We have an analyst network of other 550 members and an online collaboration site which has now grown significantly with nearly 15,000 members – all who are passionate about the use of SPC to benefit patient care.

The Making Data Count materials were recently translated into Norwegian and launched at the National Patient Safety conference in Oslo. Closer to home NHS England has issued guidance to boards of both NHS Trusts and ICBs which recommend the use of SPC over traditionally based RAG reporting and maybe more importantly has adopted SPC to monitor national performance rather than RAG reporting which has been used for many years. I am hopeful that this last change will have a significant impact on the conversations which take place between NHS England, ICBs and healthcare providers.

Your most recently published paper which demonstrated that boards are adopting SPC without even being trained by us has been incredibly helpful and I have no doubt that the various pieces of research that you have independently undertaken have played a part in some of these very exciting changes at national level.

So thank you again for all of your support – your work has very much strengthened the evidence base for the benefits of using SPC in the NHS and the independent evaluation of the Making Data Count programme is very important as it provides additional credibility to the programme. I look forward to continuing our collaboration over the coming months and years.”

# Announcing the 2025 ARC West Midlands Implementation Science Masterclasses

*Dr Justin Aunger & Dr Laura Kudrna*

**W**e know that many researchers want to use principles from implementation science but do not feel equipped to do so. At ARC West Midlands, we are developing an applied course on implementation science to better equip the researchers of tomorrow with the skills they need to draw on implementation science across a range of interdisciplinary areas. While several courses exist from other institutions that aim to address this issue, we found that they are often: (1) expensive, (2) only comprise of written materials, or (3) are not intended for a UK context. The ARC WM is ideally positioned to fill this gap by bringing together a wealth of knowledge from a range of experts about how implementation science can be used across different disciplines including health services research, global health, and AI.

Our course will be free and online, leveraging applied examples from experts in the field, which we are calling '*Masterclasses*'. We are aiming to launch the course in the 2025/26 academic year following a series of five Masterclasses taking place over the course of 2025. Please see our website for a timetable, which we will update as different Masterclasses take place: <https://implementationscience.wordpress.com/>.

Our first Masterclass is taking place on Tuesday 4<sup>th</sup> February, 1-2pm, both online and in person at the University of Birmingham campus. This Masterclass will provide an introduction to implementation science by Professor Amy Grove. Amy Grove is a leader in Implementation Science and Health Technology Assessment who has recently joined the University of

Birmingham where she is leading a new Centre for Implementation Science. We hope you will register for this.

To register for this seminar, please complete this form: <https://forms.office.com/e/vKQNTDvvzz>

We will keep you informed about future Masterclasses as they are announced via this blog and through our social media channels.



UNIVERSITY OF  
BIRMINGHAM

## Implementation Science Masterclass Series: Introduction

**Professor Amy Grove**  
4th of February, 13:00-14:00

Online and in person - registration required below



Register at:  
[implementationscience.wordpress.com](https://implementationscience.wordpress.com)

We implement  
**We activate**  
[birmingham.ac.uk](https://birmingham.ac.uk)

# Latest News and Events

## King's New Years Honours List

Congratulations to Prof Sara Kenyon, our Maternity theme lead, who has been awarded an MBE for services to midwifery in the 2025 New Year's Honours List. Read about her work at:

[www.birmingham.ac.uk/news/2024/pioneer-in-midwifery-awarded-mbe-for-dedicated-career-in-maternal-health](http://www.birmingham.ac.uk/news/2024/pioneer-in-midwifery-awarded-mbe-for-dedicated-career-in-maternal-health)

## Health Services Research UK Conference 2025

The 18th annual HSR UK conference will be held next year at Newcastle University over 2-3 July. This conference covers the most pressing topics across health and social care services, and offers opportunities to engage with cutting-edge research, build networks, and reach a wide audience of peers, funding agencies, government think-tanks, journals, industry, consultancy and the third sector.

The call for submission of proposed research presentations is now open until **20 January 2025**. Proposals can be 10-minute research discussion oral sessions; 7-minute pecha kucha rapid fire oral sessions; or poster presentation with or without a 10-minute walk-round session.

For more information, and to submit a proposal, please visit: [hsruk2025.org](http://hsruk2025.org).

## Latest National NIHR ARC Newsletter

The December round-up issue of the NIHR ARCs Newsletter is now available at: [http://eepurl.com/i35\\_tc](http://eepurl.com/i35_tc).

This issue includes research suggesting new fathers need better support with transition to fatherhood; variation in regional access to ADHD treatment in young adults; and creation of a diagram showing how young people can get involved in research.

To subscribe to future issues, please visit: <https://tinyurl.com/ARCsnnewsletter>.



## NIHR Research for Patient Benefit Competition

The latest competition for the NIHR Research for Patient Benefit programme is now open. This sees the launch of two highlight notices: addressing specific regional health challenges in the East of England and South West regions; and [addressing early action to prevent poor health outcome](#) with a focus on tackling inequality in prevention/early detection or intervention/management of people most at risk.

Further information, including how to apply, can be found at: [nihr.ac.uk/funding/research-patient-benefit-competition-56/97024](http://nihr.ac.uk/funding/research-patient-benefit-competition-56/97024)

Deadline for application is 1pm on **5 March 2025**.

## ARC WM & Midlands PSRC Seminar Series

Our seminar series will now continue as a joint partnership between ARC West Midlands and Midlands PSRC. Although topics have not yet been finalised, the dates for 2025 are:

- 27 February 2025, 12:00pm-1:00pm
- 7 April 2025, 2:00pm-3:00pm  
- [Dr Justin Aunger](#)
- 20 May 2025, 11:00am-12:00pm  
- [Dr Punith Kempegowda](#)
- 4 July 2025, 10:00am-11:00am  
- [Dr Hayley Crawford](#)

- 24 September 2025, 12:00pm-1:00pm  
- [Dr Julia Gaulty](#)
- 6 November 2025, 10:00am-11:00am
- 9 December 2025, 1pm-2pm

Further information will be publicised nearer the dates.

For details on how to attend, please contact: [arcwm@contacts.bham.ac.uk](mailto:arcwm@contacts.bham.ac.uk)

## SafetyNet PhD Networking Event

SafetyNet are holding a Patient Safety Research Collaboration (PSRC) PhD Networking Event at Imperial College, London on **Wednesday 19 March 2025**.

Submission for abstract proposals is now open for posters or 15-minute presentations.

If you are interested, please email [Sopna Choudhury](mailto:Sopna.Choudhury@bham.ac.uk) for more information: [s.m.choudhury.1@bham.ac.uk](mailto:s.m.choudhury.1@bham.ac.uk).

Deadline for abstract submission is **31 January 2025**.

## PHRESH Collaboration Event

The [PHRESH \(Public Health REsearch\) consortium](#) will be hosting a day of inspiration, connection and collaboration at The Exchange in Birmingham on **5 February 2025**. This event aims to bring together creative minds to make a difference in the community, focussing

on influencing public health policy and practice.

For further information, and to register to attend, please visit: [eventbrite.co.uk/e/phresh-collaborations-influencing-public-health-policy-and-practice-tickets-1048710680877](https://eventbrite.co.uk/e/phresh-collaborations-influencing-public-health-policy-and-practice-tickets-1048710680877)

## Save the Dates: National ARC Webinars

Following the success of the national ARC webinar series in 2024, the NIHR are running a third series in 2025 on the provisional themes of health inequalities and/or mental health on the following dates:

- Wednesday 7 May 2025
- Wednesday 11 June
- Wednesday 9 July

We will update you with more information in the coming months.

# Recent Publications

Aiyegbusi OL, McMullan C, Hughes SE, Turner GM, Haroon S, Hotham R, Brown K, Alder Y, Agyen L, Buckland L, Camaradou J, Chong A, Jeyes F, Matthews KL, Moore P, Ormerod J, Price G, Saint-Cricq M, Stanton D, Walker A, Calvert MJ. [Implementation of patient and public involvement and engagement \(PPIE\) for the therapies for long COVID in non-hospitalised individuals \(TLC\) project.](#) *Res Involv Engagem.* 2024; **10**(1): 120.

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