

NIHR | Midlands Patient Safety Research Collaboration

Supporting Patient Choice: Desig Decision Aids or Design a Servic	1
Qui	4
The Three Musketeers o	5
Patient Decision Aid	

Slow Recovery of Surgical Volumes Post-COVID	8
Maternal Mortality at Midlands PSRC	10
Festival of Dementia Research Event	11
Latest News & Events	13
Recent Publications	16



Supporting Patient Choice: Design Decision Aids or Design a Service

Richard Lilford, ARC WM Director & Midlands PSRC Co-Director; Pamela Nayyar, Research Project Manager; Saba Tariq, Post-doctoral Fellow

The Problem

ost work concerning methods to support patient choice concerns decision aids.[1, 2] A decision aid is a tool to help people make informed choices among healthcare options. It provides evidencebased information about the potential risks and benefits of different interventions and helps clarify what matters most to patients. Within the NIHR Midlands PSRC, we are reviewing the literature on decision aids to inform choice in pregnancy. We have found 18 studies comparing decision aids with care as usual. These studies cover various choice scenarios, such as planned caesarean section vs planned vaginal delivery after a previous caesarean, and choice of birth for a large baby.

All studies showed benefits for the decision aids compared to care not supported by the decision aids, over various scaled outcomes, such as knowledge, satisfaction with care, and satisfaction with the decision made. Whilst the studies described the interventions in detail, accessing the decision aids proved challenging due to a lack of relevant permissions required for access and inactive links to websites where the information was originally available. While a few studies (e.g. Kuppermann, et al. [3]) included the decision aid in the Supplementary Material, we can find no evidence that the decision aids that were the topic of enquiry in the various studies have been sustained in practice.

Furthermore, a decision aid does not function in isolation from the service – staff have a role in providing psychological support and in answering questions, no matter how good the decision aid artefact may be. Clinical staff have a duty to inform people of their options, and then they are responsible for carrying through the selected management plan. Yet there is more literature on decision aids as an artefact than on staff education to support patient choice, irrespective of whether a decision aid was or was not deployed. A rare exception is an education package to improve decision support in the field of cardiovascular medicine. [4, 5]

All of the above considerations lead to a conclusion that what is needed is service design to support patient choice by providing a complete package of structures and processes to support choice, and to integrate decision aids into a coherent package. So, what are the elements that should be included and how should they be integrated? To make our task tractable, we will situate our endeavour in the context of common option sets that arise in the third trimester of pregnancy.

A Service to Support Patient Choice in the Third Trimester of Pregnancy

The components of an integrated choice support service are represented in the Figure on the next page. These components consist of the following:

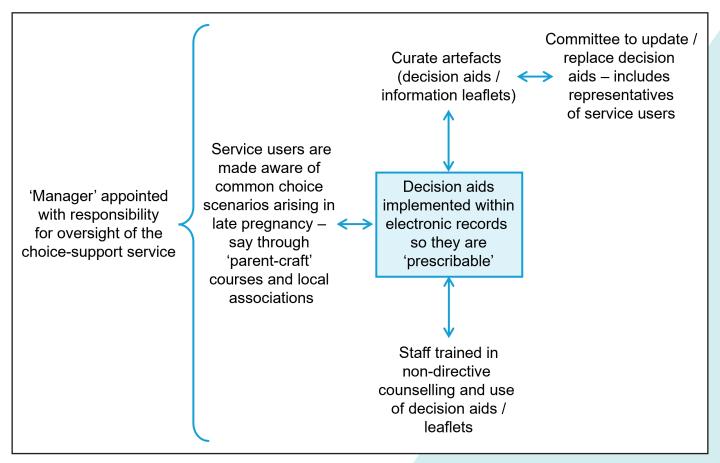


Figure: Representation of a Choice Support Service

1. Decision Aids

Given that decision aids are effective, their use should be supported by the service. Services should therefore select a set of evidence-based and institutionally-endorsed decision aids. The set should include aids dealing with common decision scenarios, such as mode of delivery (e.g. for persistent breech presentation, putatively large baby, previous caesarean section) and place of delivery (e.g. home vs midwife unit vs obstetric unit). Ideally, the decision aids should conform to the International Patient Decision Aid Standards (IPDAS), which cover issues such as the optimal method of presenting probabilistic information.

2. Selection of Decision Aids

Many of the above choices are catered for by existing decision aids. However, knowledge evolves, and decision aids may therefore become obsolete. The corollary is that the service needs to implement some type of standing committee or management structure to ensure that a selection is made from those available (ideally from professional societies or official bodies such as NICE in England). The service should be free to make justified amendments to these aids and to participate in national or international endeavours to produce or update decision aids.

3. Curation of Decision Aids

The above cannot be a one-off exercise but must be repeated and updated at regular intervals. The selection and maintenance of the decision aid library should be a service function, analogous to the maintenance of the pharmaceutical inventory. Thus, a member of staff should assume overall responsibility for the service and should be assisted by an advisory committee.

4. Ensuring Availability of Decision Aids

As stated above, decision aids, like clinical guidelines, are ephemeral in the sense that they

tend to disappear and become inaccessible. This problem can be easily solved now that the services are replete with electronic notes. Thus, decision aids should be incorporated in the notes so that they are 'prescribable' when the need arises. Again, the management structure suggested above could be responsible for selection, maintenance and incorporation of decision aids.

5. Staff Education

Offering patient choice is not a simple or straightforward matter since it is timeconstrained, must balance information volume with overload, and cater for different levels of health literacy (see the following article). [6] Thus, staff training should be encouraged as a crucial part of Continuing Professional Development. Such training may benefit from role-play and/or video-presentations of choice scenarios under different constraints. Such roleplay can introduce strategies for coping with challenges, such as time constraints or a situation where the decision-makers feel overwhelmed. For example, the strategy of offering a further appointment where the decision-maker is invited to bring a relative or friend, or when an interpreter may be present.

6. Advance Notice

While simulating choice scenarios in our work programme, it became apparent that there are several choice scenarios to which a sizable proportion of the pregnant population will be exposed. For example, some services set the definition of a predicted large baby at the 90th centile, meaning that approaching 10% of the population, for whom an intervention is not otherwise indicated, will be offered a choice of birth method. Some may argue that the choice of an alternative birth method should be offered (not just open) to all women. These considerations

invite the question 'why wait until the scan has shown a large baby before introducing the choice?' Therefore, we would invite readers to consider the idea that all pregnant women should have some advance warning of choices that often arise closer to the time of birth, and of some of the benefits and risks of alternatives — sources of further information could be made available at this time. At least we think that the option of 'advance notice' should be discussed with service users. Such a service may be particularly useful for people with special needs.

7. Managerial Oversight and Governance

One member of staff – such as a specialist obstetrician or consultant midwife – should be designated to assume overall responsibility for the patient information service. This person should report to the board through the institution's overall governance structure.

Conclusion

In this article we advance the argument that offering choice is a subtle art that needs to be built into the overall design of maternity services. Our proposed service design is represented in the above figure. Safety has a nuanced meaning in the context of choice – safety is not simply a question of minimising risk. It is a question of selecting the option that minimises the overall risk arising from each individual risk *weighted* by its preference.[7] Offering choice in a non-directive emotionally supportive way is one of the most difficult parts of practice. It is a task that should be supported in the way services are designed.

References:

- Lilford RJ. <u>Decision Aids to Help People Make</u>
 <u>Difficult Decisions</u>. NIHR ARC West Midlands
 and Midlands PSRC News Blog. 2024; 6(5): 1-4.
- 2. Lilford RJ. <u>Implementing Decision Aids in</u>
 <u>Routine Clinical Pathways</u>. *NIHR ARC West Midlands and Midlands PSRC News Blog*. 2025;
 7(1): 1-3.
- 3. Kuppermann M, Kaimal AJ, Blat C, et al. Effect of a Patient-Centered Decision Support Tool on Rates of Trial of Labor After Previous Cesarean Delivery: The PROCEED Randomized Clinical Trial. JAMA. 2020; 323(21): 2151–9.
- 4. Pollak KI, Olsen MK, Yang H, et al. <u>Effect of a Coaching Intervention to Improve Cardiologist</u>

- Communication. A Randomized Clinical Trial. *JAMA Intern Med.* 2023; **183**(6): 544-53.
- 5. Lilford R.J. <u>One-to-One Coaching Improves</u>
 <u>Cardiologists' Communication Style</u>. *NIHR ARC West Midlands News Blog*. 2023; **5**(4):6.
- 6. Lilford R.J. The Information Paradox at the Heart of Non-Directive Counselling. NIHR ARC West Midlands and Midlands PSRC News Blog. 2024; 6(4): 1-3.
- 7. Lilford R, Girling A, Stevens A, Almasri A, Mohammed MA, Braunholtz D. <u>Adjusting for treatment refusal in rationing decisions</u>. *BMJ*. 2006; **332**(7540): 542-4.

Quiz

What is the name of the mosquito that has recently evolved in the horn of Africa and which: 1) bites in day time; 2) lives mostly in cities; and 3) is resistant to insecticides?

email your answer to: arcwm@contacts.bham.ac.uk

Answer to previous quiz: The Apgar score takes its name from the original developer **Dr Virginia Apgar**. The list of criteria is now a backronym of her surname - Appearance, Pulse, Grimace, Activity and Respiratory effort.

Congratulations to Alan Cohen who was first to answer correctly.

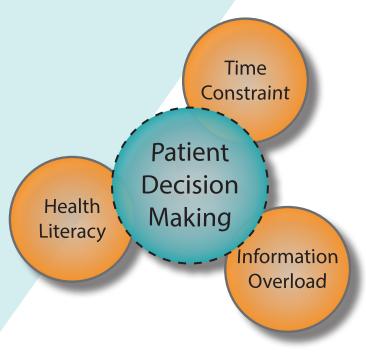
The Three Musketeers of Patient Decision Aids: Time Constraints, Health Literacy, and Information Overload

Saba Tariq, Post-doctoral Fellow, University of Birmingham

aking a balanced decision in every situation is an art, and when it comes to our health, it becomes very difficult because multiple factors are involved. Like any other situation, some aspects are within our control, while others are external and beyond our influence. Interplaying with these factors and effectively using them can assist both healthcare professionals and patients to make sound decisions. Lilford, et al. have previously discussed the significance of decision aids in maternity care, emphasising their role in improving patient satisfaction and reducing decisional conflict. [1, 2] Their work also explored how one-to-one coaching enhances communication styles among healthcare professionals. Additionally, paradox of non-directive counselling highlighted challenges in providing unbiased information while ensuring informed decision making. In this blog, I will discuss three important factors in patient decision-making that, if balanced correctly, can lead to better outcomes.

The First Musketeer: Time Constraint (Athos, the Wise but Limited Leader)

Time constraints in clinical settings often impede comprehensive patient discussions. Healthcare professionals have little time to explain options, which leaves patients struggling to make informed decisions. When time is limited, people often amplify the framing effect, becoming more willing to take risks in loss frames and more cautious in gain frames. Shorter deadlines increase the chances of making impulsive decisions based on how options are framed. When individuals face



higher pressure to make a decision quickly, they rely more on their initial instincts rather than rational analysis.[3] Therefore, neutral framing of time is very important. The maternity theme of the NIHR Midlands PSRC is working on a project to help patients make optimal decisions, and there is a need to use neutral framing in this context to avoid influencing decisions based on fear or urgency.

For example, instead of saying, "if you wait, then your baby may grow too big, increasing risks," re-frame it as "early decision-making allows for more options and better preparation."

Primary care physicians frequently feel that time constraints hinder their ability to engage in thorough shared decision-making with patients. [4] It creates pressure in the decision-making process, particularly in healthcare settings where patients and clinicians need to make informed choices quickly. Using a multi-modal approach that combines verbal discussions with written leaflets, infographics, and digital resources is essential. These methods can significantly improve the decision-making process. We should guide patients through all these options, as leaflets and infographics provide visual representation of key information that patients can easily digest. Additionally, we can reschedule appointments and suggest credible web pages, allowing patients to explore the information at their own pace, without feeling rushed, enabling them to make better decisions.[5]

The Second Musketeer: Health Literacy (Porthos - The Strong but Needs Clarity)

Patients with low health literacy may struggle to understand complex medical information, which hinders their ability to comprehend the details, risks, and associated benefits, leading to suboptimal decisions. McCaffery, et al. recommended in their research that patient decision aids should be developed to cater to patients with different health literacy needs.[6] They suggested incorporating plain language, visual aids, and interactive elements can enhance comprehension and usability for patients with limited health literacy. Ensure that the language used in the patient decision aid is suitable for the comprehension levels of the majority of the target audience by employing a quantifiable strategy (e.g., Flesch-Kincaid, Simple Measure of Gobbledegook (SMOG), Fry Readability Formula (or Fry Readability Graph), or other recognised methods).[7] These tools offer a quantifiable means to align the material's complexity with the reading abilities of the intended audience. Nevertheless, it's crucial to recognise that while these formulas provide valuable insights, they have limitations. In short, we can tackle health literacy by simplifying the information for the patient, ensuring that we explain it in an easyto-understand language. After explaining, we should check their understanding by asking,

"What did you understand from this?" or "Is there anything you would like me to explain again?"

Additionally, we can schedule follow-up appointments to give them time to process the information and return with any questions. We can also suggest they bring a family member or someone knowledgeable about these matters for support. Furthermore, we can send them an email summarising the key points and inviting them to reach out if they need further clarification.

It is important to present health information in a way that most adults can read, comprehend, and make informed decisions.

Information Overload (Aramis - The Idealist, but Overwhelmed by Choices)

Excessive data can confuse rather than clarify, making decision-making overwhelming instead of empowering. The information doctors provide isn't always equally important for every patient. One type of information may be crucial for one set of patients but not for others because their circumstances differ. Providing too much information can overwhelm patients, making it difficult for them to make decisions. So it's essential to tailor the tone, type of information, and context to each patient's unique circumstances.[8]

We can adopt strategies to avoid information overload, helping patients make better decisions. It's crucial to provide a clear, balanced, and neutral presentation with objective, complete, and evidence-based information. Highlight key features and present information side by side to allow patients to compare benefits and risks easily. Mixed media, like videos, can be more engaging and unbiased. Using pictographs and

numerical formats helps patients make better decisions. Avoid words that favour one option over another and present positive and negative aspects equally. Chunk the information into layers to prevent overload and offer progressive disclosure for step-by-step details. Tailor the information to the patient's health literacy level, ensuring it's digestible for them.[9]

communication, turning challenges into opportunities for better engagement. The true essence of patient decision aids lies in presenting information and guiding patients toward decisions aligned with their values, preferences, and unique health journeys. The balance we strike today between depth and acceptability will define the future of patient-centred care.

These decision aids are vital tools that bridge the gap between patient empowerment and medical knowledge. Their effectiveness relies on addressing three key aspects: time constraints, health literacy, and information overload. By effectively addressing these, we can streamline decision-making through clear, accessible Therefore, we must empower individuals to make confident, clear, and controlled choices. Solutions should address all three simultaneously, improving communication, simplifying complex information, and allowing sufficient time for decision-making.

References:

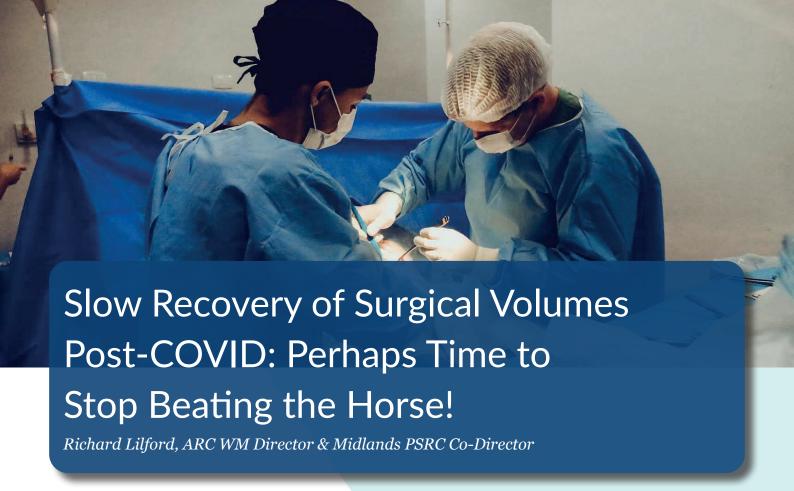
- 1. Lilford R. One-to-One Coaching Improves

 <u>Cardiologists' Communication Style</u>. NIHR ARC

 West Midlands News Blog. 2023; 5(4): 6.
- 2. Lilford R. <u>The Information Paradox at the Heart of Non-Directive Counselling</u>. *NIHR ARC West Midlands & Midlands PSRC News Blog*. 2024; 6(4): 1-2.
- 3. Diederich A, Wyszynski M, Traub S. <u>Need, frames, and time constraints in risky decision-making</u>. *Theory Decision*. 2020; **89**(1): 1-37.
- 4. Konrad TR, Link CL, Shackelton RJ, et al. <u>It's</u> about time: physicians' perceptions of time constraints in primary care medical practice in three national healthcare systems. *Med Care*. 2010; **48**(2): 95-100.
- 5. Kline A, Wang H, Li Y, et al. <u>Multimodal machine</u> learning in precision health: A scoping review.

 NPJ Digit Med. 2022; **5**(1): 171.

- 6. McCaffery KJ, Holmes-Rovner M, Smith SK, et al. Addressing health literacy in patient decision aids. BMC Med Inform Decis Mak. 2013; 13(s2): s10.
- 7. McCaffery K, Sheridan S, Nutbeam D, et al. Addressing Health Literacy. In: Volk R & Llewellyn-Thomas H (eds). 2012 Update of the International Patient Decision Aids Standards (IPDAS) Collaboration's Background Document. Chapter J.
- 8. Lilford R. <u>Decision Aids to Help People Make</u>
 <u>Difficult Decisions</u>. *NIHR ARC West Midlands & Midlands PSRC News Blog*. 2024; **6**(5): 1-4.
- 9. Martin RW, Brogård Andersen S, O'Brien MA,et al. Providing balanced information about options in patient decision aids: an update from the International Patient Decision Aid Standards. Med Dec Mak. 2021; 41(7): 780-800.



that have shown only very gradual recovery of surgical volumes following the COVID-19 pandemic in the UK. Our findings can be interpreted as showing that, while the NHS has been able to recover, this has taken place gradually over four years – there has been a 'hang-over effect' from COVID.

Speculation on the underlying reasons for the sluggish recovery

The three classical supply-side factors of production are plant and equipment, human resources, and materials (such as medicines and reagents). These have all remained in place over the pandemic. However, there is a fourth, elusive factor – how these three factors are brought together. Here we offer a theory (albeit with little evidence to confirm it!).

The NHS lacks market incentives. This is arguably a good thing, given endemic market failure in healthcare services.[1,2] However, successive governments have tried to compensate for this by top-down performance management and inspections replete with performance targets, sacking of chief executives, financial incentives and so on. However, this has been excessive, leading to all manner of gaming – the latter showing up again and again in massive bunching of organisations that met the target only by a whisper.[3-6] Meanwhile, excessive medical autonomy has been over-corrected with disbandment of medical teams and rigid job plans that displace intrinsic motivation with extrinsic motivation. The Secretary of State in England has recently doubled-down on performance management to reward or sack hospital chief executives.[7] Perhaps this is the wrong direction of travel; perhaps the time has come for a less strident, more 'emotionally intelligent' form of leadership that empowers local services in the manner that is thought to have transformed the US Veterans Health Administration hospitals under the leadership of Kenneth Kizer.[8]

References:

- 1. Propper C. Quasi-markets, contracts and quality in health and social care: the US experience. In: Le Grand J, Bartlett W (Editors). *Quasi-markets and social policy*. Red Globe Press, 1993; 35-67.
- 2. Akerlof GA. The market for "lemons": quality uncertainty and the market mechanism. *QJ Econ*. 1970; **84**: 488-500.
- 3. Liaqat A, Gallier S, Reeves K, et al. Examining organisational responses to performance-based financial incentive systems: a case study using NHS staff influenza vaccination rates from 2012/2013 to 2019/2020. BMJ Qual Saf. 2022; 31: 642-51.
- 4. Gruber J, Hoe TP, Stoye G. Saving lives by tying hands: the unexpected effects of constraining health care providers.: *Rev Econ Stat.* 2023; **105**: (1): 1–19.

- 5. Takaku R, Yamaoka A. <u>Payment systems and hospital length of stay: a bunching-based evidence</u>. *Int J Health Econ Manag*. 2019; **19**: 53–77.
- 6. Fisman R, Wang Y. <u>The distortionary effects of incentives in Government: Evidence from China's "Death Ceiling" program</u>. *Am Econ J.* 2017; **9**: 202–18.
- 7. Streeting W. NHS leaders face both 'carrot and stick' in new performance drive. Department of Health and Social Care; 15 May 2025.
- 8. Payne D. <u>How Kizer healed the VA</u>. *BMJ*. 2012; **344**: e3324.

Maternal Mortality at Midlands PSRC

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

gynaecology. It has been great fun, since taking over leadership of the Maternity theme in the Midlands PSRC, getting up-to-date.

A maternal death is a death that occurs during pregnancy, or within 42 days of the end of a pregnancy, and which resulted from the pregnancy. This last criterion is open to some differences in interpretation. However, this could not fully account for the differences in mortality rates seen between countries, ranging from about two per 100,000 pregnancies in Norway and Poland, to about four times that in France, Britain and Canada, and over eight times that in the USA.

background is in obstetrics and It is difficult to know how much of these differences are due to the underlying health in the population versus the quality of healthcare. The ratio of stillbirths to maternal deaths increases as the maternal risk decreases across countries. It seems to be easier to bring down the maternal death rate than the stillbirth rate. Nevertheless, across all countries (Figure 1), including highincome countries (Figure 2), there is a very good correlation between stillbirth rates and maternal death rates.

Reference:

Boerma T, Campbell OMR, Amouzou A, et al. Maternal mortality, stillbirths, and neonatal mortality: a transition model based on analyses of 151 countries. Lancet Glob Health. 2023; 11: e1024-

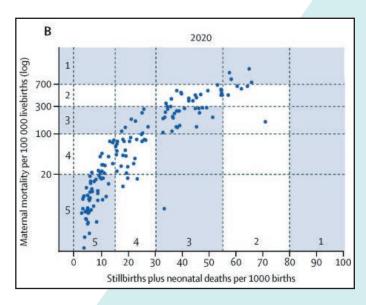


Figure 1: Maternal mortality per 100,000 live births and stillbirths plus neonatal mortality per 1000 births for 151 countries.

Data based on UN mortality estimates for 151 countries in 2020. Reproduced under CC-BY license.[1]

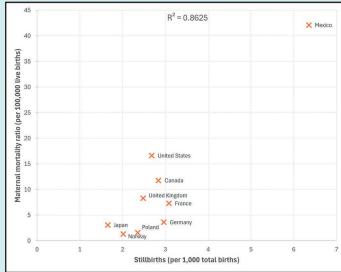


Figure 2: Maternal mortality per 100,000 live births and stillbirths per 1000 births for 9 high-income countries (2023).

Data taken from UNICEF Data Warehouse.

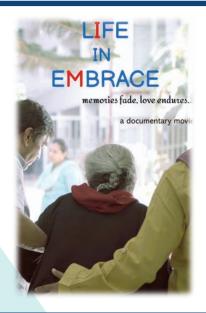
Festival of Dementia Research Event: Capturing Public Discussion of Dementia Research Through the Medium of Film and the Cinema Experience

ARC WM DEM-COMM Research Fellows and Affiliates:
Sue Molesworth (Keele University), Subhashisa Swain (Keele and Oxford Universities),
Chris Poyner (University of Birmingham), Angela Clifford (Keele University),
Paul Campbell (Keele University and Midlands Partnership University NHS Foundation Trust).

Report of the Festival of Dementia Research Event, held on 20th May 2025 at the Wade Conference Centre in Stoke-on-Trent

Event Preparation

May 19th -23rd marked the Alzheimer's Society "Dementia Action Week". The NIHR DEM COMM programme had tasked all involved ARCs to create public-facing research "festival events" during this week. Several options were considered, including the traditional Powerpoint "show and tell", however our ARC WM team agreed to take a more creative approach reflecting the "festival" spirit. Subhashisa Swain mentioned a documentary film that he was developing about cross-cultural experiences of dementia titled "Life in Embrace" and we all agreed that a film was an ideal event centrepiece. As Subhashisa progressed filming (across India and the UK!), the group linked with a Stokeon-Trent film theatre to premiere the film. To create a space for discussion about the film and dementia research, a post-show Tea and Cake party was arranged, including research poster displays and a stand for the Alzheimer's Society. The event was promoted through our networks (local charities, VCSOs, NHS trusts, GPs, academics) plus a special invitation to our dementia PPIE group (a fantastic group set up and coordinated by Chris).



Showtime!

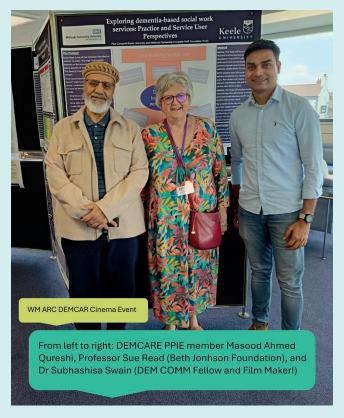
Our day arrived and the film was passed to the projectionist in readiness for a 1pm showing. Our audience took their seats, the lights dimmed and the film began. The documentary showed the experiences of several families (within India and the UK) where a family member lives with dementia. Families told their stories from the first notice of symptoms, witnessing changes over time, and plans for care in the advanced stages, and the film ended with a poem written by one of the family members in an Indian language (Odia). A warm round of applause



began as the lights came on at the end of the film. A question-and-answer session was facilitated by Subhashisa, generating thought provoking questions and reflections. One comment highlighted how the portrayal of the experiences of families had captured the "reality" of living with or alongside dementia regardless of any cultural differences. Another praised the film for its positive tone and for avoiding narratives of 'social death' that are sometimes applied to people living with dementia. Moving back into the foyer, everyone was invited for tea and cake and for the next hour there was lively discussion about the film, dementia experiences, and the research by the Fellows.

Reflections

As a group we reflected on the event, especially in the context of our experiences of other research events using traditional approaches (e.g. presenter to audience). An evident point



of difference was that the film created a space for dementia to be seen as it is, rather than as a research topic, it effectively "brought dementia in". We feel this changed the audience dynamic, people were more energized, and conversations flowed about the film, people's own experience of dementia, and about research to address current challenges. Whilst it would be impractical to create a documentary for every research event, we feel that something similar would enable this deeper and richer engagement. It may be that an existing documentary, dementia-based art, literature, or poetry, could be used to facilitate a similar shared experience.



Latest News and Events

ARC WM & Midlands PSRC Seminar Series

Our next seminar will take place on **4 July 2025**, 11-12pm with a presentation by Hayley Crawford: 'Thinking differently about behaviour that challenges in children with an intellectual disability: Introducing the Behaviour Checklist.'

Hayley's research focusses on characterising behavioural and mental health outcomes in individuals with neurodevelopmental disorders associated with intellectual disability. Her work to date has primarily focussed on understanding autism, anxiety, ADHD and behaviours that challenge in children and adults with rare genetic syndromes through describing behavioural profiles, developmental trajectories, risk markers, and mechanistic underpinnings.

Upcoming Seminars:

- 24 September 2025, 12pm-1pm, <u>Dr Julia</u>
 <u>Gauly</u> The usage, experiences and impact of the QI Notify-EmLap mobile app.
- 6 November 2025, 10am-11am
- 9 December 2025, 1pm-2pm, <u>Dr Kiyah</u> Hurley

Further information will be publicised nearer the dates.

For details on how to attend, please contact: arcwm@contacts.bham.ac.uk

Implementation Science Masterclasses

This masterclass series sees renowned experts showcasing varied case studies on applying implementation science in fields such as health service research, global health and use of AI.

Upcoming Masterclasses:

- **16 July 2025**, 1-2pm, <u>Dr Jeffry Hogg</u> AI implementation in NHS ophthalmology services.
- 26 September 2025, 1pm-2pm, Prof Roman Xu - Hybrid Type 2 Trials and AI for diabetes management.

- 22 October 2025, 1-2pm, <u>Prof Graeme</u>
 <u>Currie</u> Organisational factors
- 11 November 2025, 1-2pm, <u>Prof Iestyn</u>
 <u>Williams</u> De-implementation
- 2 December 2025, 1-2pm, <u>Prof Robin Miller</u>
 Understanding process.

For further details and to register to attend, please visit: https://implementationscience.wordpress.com/

Latest National NIHR ARC Newsletter

The June issue of the NIHR ARCs Newsletter is now available at: http://eepurl.com/jfJ2U-/. It features events to mark Dementia Action week; national recommendations to transform mental health support for children and teens; and an antibiotics pathway to reduce hospital stays for newborns.

To subscribe to future issues, please visit: https://tinyurl.com/ARCsnewsletter.



Red for Research

On Friday 20 June the NIHR are recognising all those who participate in, support and undertake research, both on the front line and behind the scenes with their #Red4Research campaign.

This campaign aims to get as many people as possible wearing red to demonstrate their support and appreciation for all those involved in research. It is an opportunity to showcase and celebrate the phenomenal work, learning legacy and innovative treatments/systems/techniques that have arisen from R&D.

NIHR colleagues will be wearing red and sharing their photos via social media with the hashtag #Red4Research.



ICIC26: International Conference on Integrated Care

The 26th International Conference on Integrated Care will take place on **13-15 April 2026** in Birmingham, in partnership with the International Journal of Integrated Care and the University of Birmingham.

The conference will bring together researchers, practitioners, people with lived experience, clinicians and managers from the UK around the world who are engaged in the design and delivery of integrated health and social care. They will explore how integrated care can respond to the needs of diverse people and communities, embrace the skills and knowledge of diverse professionals and practitioners, and develop diverse and innovative interventions which build on the strengths of people and technology.

For more information, please visit: https://integratedcare



NIHR Pre-Application Support Funding

NIHR ARC West Midlands have pre-application support funding available for individuals to enhance their chances of making a successful application to a future NIHR career development scheme.

The deadline for applications is **30 June 2025**. Applicants must be able to complete their award by March 31st 2026.

For more information, and how to apply, please visit: arc-wm.nihr.ac.uk/research-capacity-development/nihr-pre-application-support-funding/

INSIGHT: Inspiring Students into Research - West Midlands

The deadline for applications for the NIHR INSIGHT for West Midlands scheme has been extended until **24 June 2025**.

This scheme is for early career registered healthcare, social work or public health professionals interested in postgraduate research. Both full- and part-time studentships are available, with masters programmes at various West Midlands universities, and tuition fees and a stipend provided.

For more information, and how to apply, please visit: arc-wm.nihr.ac.uk/insight-west-midlands/

NIHR ARC Seminar Series - Creative Arts & Dementia

The latest NIHR ARC Seminar Series will be held online on Wednesday 9 July 2025, 1-2pm looking at the use of *creative arts for people with dementia*. Speakers will discuss music therapy, singing and dancing interventions, and using

creative arts, followed by a chance for questions.

For further information, and to book, please visit: eventbrite.co.uk/e/creative-arts-for-dementia-tickets-1248698794709

Implementation Conference 2026

Save the date for the next Implementation Conference, which will be held on **25-26 June 2026** in Bristol.

This conference will be focussed on *Inclusive Implementation - making it happen*, and run by ARC West and ARC South West Peninsula, with support from the UK Implementation Society.



Recent Publications

Ashworth J, Cornwall N, Harrisson SA, Woodcock C, Nicholls E, Lancaster G, Wathall S, Laing L, Helliwell T, Jowett S, Kigozi J, Mallen CD, Avery A, Knaggs R, Pincus T, White S, Jinks C; PROMPPT team. Proactive clinical review of patients taking opioid medicines long term for persistent pain led by clinical pharmacists in primary care teams (PROMPPT): a non-randomised mixed methods feasibility study. Pilot Feasibility Stud. 2025; 11(1): 53.

Atkin C, Perrett M, Cooksley T, Varia R, Holland M, Knight T, Subbe C, Lasserson DS, Sapey E. Provision of medical same day emergency care services within the UK: analysis from the Society for Acute Medicine Benchmarking Audit. *BMJ Open.* 2025; **15**(4): e094580.

Awan H, Corp N, Kingstone T, Chew-Graham CA. Social determinants of distress in South Asian men with long-term conditions: a qualitative study in primary care. *Br J Gen Pract*. 2025; **75**(755): e397-e405.

Bosque-Mercader L, Conroy S, Lasserson D, Mannion R, Nicodemo C, Wittenberg R. Resilience of the acute sector in recovery from COVID-19 pressures. Soc Sci Med. 2025; **375**: 118062.

Byrne AK, Twohig H, Muller S, Scott IC. Healthcare use and its variation in people with fibromyalgia: a systematic review protocol. *Prim Health Care Res Dev.* 2025; **26**: e42.

Camacho EM, Shields GE, Eisner E, Littlewood E, Watson K, Chew-Graham CA, McMillan D, Gilbody S. <u>Case-finding with the anxiety subscale of the Edinburgh Postnatal Depression Scale in an observational cohort: Sensitivity, specificity, and cost-effectiveness.</u> *J Affect Disord.* 2025; **381**: 84-91.

Coope C, Baker D, Lippiett KA, Moult A, Scott LJ, Chilcott S, Turner A, Jinks C, Portillo MC, Dziedzic K, Mann C, Byng R, Scrimgeour G, Salisbury C, Johnson R. <u>Impact of a comprehensive review template on personalised care in general practice</u>

for patients with multiple long-term conditions: a mixed-methods evaluation. *BJGP Open.* 2025.

Douthwaite M, Morelli A, Kenyon S, Sanders J, Rowe R. <u>Intermittent auscultation fetal monitoring practice in different UK birth settings: a cross-sectional survey</u>. *BMC Pregnancy Childbirth*. 2025; **25**(1): 446.

Drahos J, Boateng-Kuffour A, Calvert M, Levine L, Dongha N, Li N, Pakbaz Z, Shah FT, Ainsworth N, Martin AP. Health-related quality of life and economic impacts in adults with transfusion-dependent β-thalassemia: findings from a prospective longitudinal real-world study. *Qual Life Res.* 2025.

Drahos J, Boateng-Kuffour A, Calvert M, Valentine A, Mason A, Li N, Pakbaz Z, Shah FT, Ainsworth N, Martin AP. <u>Health-related quality of life and economic impacts in adults with sickle cell disease with recurrent vaso-occlusive crises: findings from a prospective longitudinal real-world survey. Qual Life Res. 2025.</u>

Faux-Nightingale A, Saunders B, Burton C, Chew-Graham CA, Somayajula G, Twohig H, Welsh V. Perceptions and Significance of Long Covid Diagnoses From the Perspectives of Children and Young People With Long Covid, Their Parents and Professionals. Health Expect. 2025; 28(3): e70318.

Fayehun O, Apenteng P, Umar UA, Adebayo KO, Owoaje E, Sartori J, Popoola O, Nnabuife U, Oladejo A, Odubanjo O, Ayandipo O, Odukogbe AT, Irabor D, Ijitola J, Muhammad AB, Haruna I, Ajiya A, Suleiman AR, Muhammad ID, Adamou N, Abdullahi NG, Muhammad S, Tijjani I, Nagwamutse TN, Abdullahi SU, Shittu L, Ado KA, Umar AA, Bello AS, Yakasai IA, Omigbodun A, Lilford R. <u>Diagnosis of cancer in the South and North of Nigeria: duration and causes of delay</u>. *BMC Health Serv Res.* 2025; **25**(1): 738.

Fitzpatrick KE, Bowen L, Li Y, Kwok CH, Alderdice F, Dealmeida S, Gale C, Kenyon S, Quigley MA, Sanders J, Siassakos D, Carson C. The maternal postnatal six-week check in women with epilepsy: Does the prevalence or subsequent postpartum health differ from the general postnatal population? *PLoS One*. 2025; **20**(5): e0323135.

Grumitt G, Man R, Vance JL, Turner A, Morris RK, Morton VH; CHAPTER group. <u>Outcomes of suture material, suture technique and tissue adhesives for repair of childbirth-related perineal trauma: A systematic review and meta-analysis</u>. *Eur J Obstet Gynecol Reprod Biol*. 2025; **312**: 114086.

Harrison R, Wynne Jones G, Parsons V, Madan I, Chew-Graham C, Pemberton J, Mansell G, Walker-Bone K, Foster NE, Saunders B; wider WAVE trial team. <u>Stakeholder perceptions of supporting patients' return-to-work in primary care: a qualitative study</u>. *BJGP Open*. 2025.

Harrisson S, Myers H, Wynne-Jones G, Bajpai R, Bratt C, Burton C, Harrison R, Jowett S, Lawton SA, Saunders B, Beard D, Bucknall M, Chester R, Heneghan C, Huckfield L, Lewis M, Mallen C, Pincus T, Rees JL, Roddy E, van der Windt D. Clinical and cost-effectiveness of a personalised guided consultation versus usual physiotherapy care in people presenting with shoulder pain: a protocol for the PANDA-S cluster randomised controlled trial and process evaluation. *BMJ Open.* 2025; **15**(5): e100501.

Hawarden A, Bullock L, García ML, Hartasanchez SA, Maraboto A, Jinks C, Kunneman M, Hargraves I, Horne R, Montori VM, Paskins Z. Getting to what matters for people with osteoporosis in clinical consultations with and without conversation aids: A videographic analysis. Patient Educ Couns. 2025; 137: 109171.

Hieke G, Black GB, Yargawa J, Vindrola-Padros C, Gill P, Islam L, Williams ED, Braun S, Whitaker KL. South Asian patient experiences of professional interpreting service provision in general practice in England: a qualitative interview study. *Int J Equity Health*. 2025; **24**(1): 104.

Hurley KL, Jolly K, Brown H, Scott S, Akhter Z, Dyer E, Nguyen G, Lake AA, Möller-Christensen C, Flint N, Baker A, Brennan-Tovey K, Dickie S, Gibson E, Jackson C, Loopstra R, Nagra H, Rankin J, Williams D, Wiseman A, Heslehurst N. Food, Pregnancy & Me: Exploring food insecurity in pregnancy in the UK to inform future public health intervention needs—A mixed-methods study protocol. *PLoS One*. 2025; **20**(5): e0321638.

Jones E, Quinn L, Tanner JR, Jankovic J, Berrisford G, MacArthur C, Taylor B. <u>Prevalence and incidence of moderate and severe mental illness in the second postpartum year in England (1995-2020): a national retrospective cohort study using primary care data. Lancet Reg Health Eur. 2025; **53**: 101312.</u>

Jones L, Delicate A, Waigwa S, Hodgetts Morton V, Morris RK, Whitehurst J, Hillman S; Chapter Collaborative Group. Exploring views and experiences of childbirth-related perineal trauma: a qualitative study protocol for developing a wound management tool and care pathway. *BMJ Open.* 2025; **15**(4): e088248.

Joseph L, Gaitonde R, Retnakumar C, Krishnan A, Lekha TR, Sasidharan N, van Rensburg A, Levitt N, Upakdee N, Thulaseedharan JV, Valamparampil MJ, Harikrishnan S, Greenfield S, Gill P, Davies J, Manaseki-Holland S, Jeemon P. Non-communicable disease multi-morbidity inpolicies from India, Thailand, and South Africa: A comparative document review. *J Multimorb Comorb*. 2025; **15**: 26335565251330371.

Kyte D, Fletcher BR, Horton M, Damery S, Aiyegbusi OL, Anderson N, Bissell A, Calvert M, Cockwell P, Ferguson J, Paap MCS, Sidey-Gibbons C, Turner N, Verdi R, Slade A. Development, Rasch analysis and validation of the kidney symptom burden questionnaire (KSB-Q). Clin Kidney J. 2025; **18**(5): sfaf112.

Lilford RJ, Daniels B, McPake B, Bhutta ZA, Mash R, Griffiths F, Omigbodun A, Pinto EP Jr, Jain R, Asiki G, Webb E, Scandrett K, Chilton PJ, Sartori J, Chen YF, Waiswa P, Ezeh A, Kyobutungi C, Leung GM, Machado C, Sheikh K, Watson SI, Das J. Improving primary health-

<u>care services in LMIC cities</u>. *Lancet Glob Health*. 2025; **13**(5): e795-6.

Lilford RJ, Daniels B, McPake B, Bhutta ZA, Mash R, Griffiths F, Omigbodun A, Pinto EP Jr, Jain R, Asiki G, Webb E, Scandrett K, Chilton PJ, Sartori J, Chen YF, Waiswa P, Ezeh A, Kyobutungi C, Leung GM, Machado C, Sheikh K, Watson SI, Das J. Policy and service delivery proposals to improve primary care services in low-income and middle-income country cities. Lancet Glob Health. 2025; 13(5): e954-66.

Lilford RJ, Daniels B, McPake B, Bhutta ZA, Mash R, Griffiths F, Omigbodun A, Pinto EP Jr, Jain R, Asiki G, Webb E, Scandrett K, Chilton PJ, Sartori J, Chen YF, Waiswa P, Ezeh A, Kyobutungi C, Leung GM, Machado C, Sheikh K, Watson SI, Das J. Supply-side and demand-side factors affecting allopathic primary care service delivery in low-income and middle-income country cities. Lancet Glob Health. 2025; 13(5): e942-53.

McMullan C, Haroon S, Turner G, Aiyegbusi OL, Hughes SE, Flanagan S, Subramanian A, Nirantharakumar K, Davies EH, Frost C, Jackson L, Guan N, Alder Y, Chong A, Buckland L, Jeyes F, Stanton D, Calvert M. <u>Mixed methods study of views and experience of non-hospitalised individuals with long COVID of using pacing interventions</u>. *Sci Rep.* 2025; **15**(1): 14467.

O'Mahoney LL, Routen A, Gillies C, Jenkins SA, Almaqhawi A, Ayoubkhani D, Banerjee A, Brightling C, Calvert M, Cassambai S, Ekezie W, Funnell MP, Welford A, Peace A, Evans RA, Jeffers S, Kingsnorth AP, Pareek M, Seidu S, Wilkinson TJ, Willis A, Shafran R, Stephenson T, Sterne J, Ward H, Ward T, Khunti K. The risk of Long Covid symptoms: a systematic review and meta-analysis of controlled studies. Nat Commun. 2025; **16**(1): 4249.

Pelton MK, Crawford H, Bul K, Robertson AE, de Beurs D, Rodgers J, Baron-Cohen S, Cassidy S. The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis. Suicide Life

Threat Behav. 2023; **53**(3): 426-42.

Saunders K, Nicholls W, Corp N, Kingstone T, Mughal F, Chew-Graham CA, Southam J, Fisher T. Experiences and Perceptions of Self-Harm in Rural-Dwelling Adults: A Rapid Review of Qualitative Evidence. Health Expect. 2025; **28**(3): e70268.

Shaw K, Kenyon S, Pease A, Spry J, Routledge G, Garstang JJ. <u>Child death review: understanding variations in practice using normalisation process theory</u>. *BMJ Paediatr Open*. 2025; **9**(1): e003432.

Twohig H, Franklin L, Carroll W, Corp N, Jackson E, Mallen C, Ruan B, Yapp L, Der Windt DV, Smith J. A systematic review of the clinical effectiveness of dry powder inhalers in maintenance treatment and in treatment of acute exacerbations of asthma in children. Paediatr Respir Rev. 2025:S1526-0542(25)00036-3

Unni EJ, Schougaard LMV, Aiyegbusi OL, Mate KKV, Austin EJ, Greffin K, Roberts N, Grove BE, Muehlan H; ISOQOL Clinical practice SIG PROs in Telehealth Working Group. Expert consensus on implementing patient-reported outcomes in telehealth: findings from an international Delphi study. J Patient Rep Outcomes. 2025; 9(1): 40