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Decision Aids to Help People Make Difficult Decisions

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

News Blog readers know that the NIHR Midlands Patient Safety Research Collaboration (PSRC) includes a programme of work on decision aids in maternity.

Providing non-directive counselling is a challenge. In previous News Blogs we have discussed the role of educating staff in the use of Decision Aids – they cannot replace clinical consultation, and they do not exist in isolation from the services in which they are deployed.[1] Also in your News blog we have discussed the information paradox – beyond a certain limit, providing more information clouds decision making.[2] This is a particular problem for maternity care because relevant information has to cover decision outcomes relevant to both mother and baby. The amount of information that results in overload – the point where more information clouds, rather than elucidates, decisions – will vary from one person to the next. People with low health literacy are particularly susceptible to 'overload' because they have a lower starting level of knowledge and, arguably, because they do not have an established mental framework that allows new knowledge to be easily assimilated. Our Midlands PSRC is planning a work-package specifically examining how this problem of information overload might be addressed. It is important in planning this work to take into account what is already known regarding decision aids, since some of this work is relevant to the problem posed by the information paradox. For this reason, it is worth summarising findings from research over the last 50 years. Much of this information has been described in a series of articles developed with support from the International Patient Decision Aids Standards (IPDAS) Collaboration.[3-5] Here we offer a synopsis.

Probabilities

Probabilities are central to the concept of informed decision making. Following the iconic work of researchers such as Kahneman & Tversky,[6] and the great Gigerenzer [7] we have extensive evidence on how to present probabilities (and how not to). The state of current knowledge is beautifully summarised in a review by David Spiegelhalter.[8] Probabilities should be expressed as percentages (like 5%) or perhaps simple frequencies (like 'one in twenty'), but not numbers needed to treat a harm (which are confusing).

Visual formats, such as icon panels, are effective in conveying numerical information, especially when explaining the accuracy of diagnostic tests. Icons are also helpful when disclosing very low probabilities like 1 in 2,000. If graphs are used, they should cover 0 to 1 (or 0% to 100%) on the

Y axis to avoid risks being over-estimated. It is also worth noting that asking people which format they prefer could be a disservice, because the preferred format is often not the format that maximises understanding.[9] Obviously, presentation must be 'fair', using the same denominator when multiple probabilities must be conveyed to cover salient outcomes. The study of how different numeracy skills of service users (and service providers) can be accommodated in decision aids is in its infancy [10] – a point to which we will return. The question of how, or whether, to convey uncertainty in the probabilistic estimates themselves is unsettled. Stochastic uncertainty can be expressed in numbers that equate to 95% credible intervals (for example 5% plus or minus 2%). Even more difficult, is how to express uncertainty that does not arise from imprecision but that arises from inaccuracy when experimental studies have flaws or when we have to rely on non-experimental evidence.[11]

Presentation of Information

As stated above, icons should be used to present probabilities, particularly small probabilities, such as 1 in 2,000. Also, as stated, the denominator must be defined and the same denominator used in the calculation of all probabilities presented to the decision maker. Further to this, there is good evidence that side-by-side information is better assimilated and appreciated than segmented formats. It goes without saying that aids and scripts should do all they can to avoid heuristic biases where the form of presentations influences the decision taken. For example, presenting probabilities in both negative and positive formats; 2% of people die after their operation and 98% survive the operation.

Value Clarification

In a previous News Blog, I drew attention to the work of Pauker and Pauker [12] who first elicited people's values and then used those values (utilities) to calculate *expected* utilities, which then guided further consultation. The idea is that a clinician should explore the extent to which one outcome is traded-off against another to elicit a numerical value of preference/utility/value. For example, if I would run a 10% risk of death to avoid being rendered infertile, then my utility for infertility is 0.9 on a scale between fertile life (1.0) and death (0.0). This is a standard gamble, and it is but one method to elicit a patient's preference. This topic has been reviewed recently by Witteman et al.[13] Rather than start with elicitation and utilities, as Pauker and Pauker did, most seek to get a sense of a person's preferences as the consultation proceeds. These range from a simple scale of preference across outcomes (A worse than B, B worse than C) to methods such as standard gamble or time trade-off. There is no clear sense from the literature as to which method is preferred or, indeed, what effect explicit preference measures have on understanding, knowledge or satisfaction. On rare occasions, when still in practice, I would introduce a simple standard gamble at some point in the decision process. Patients seemed to appreciate the clarity the method afforded, and it seemed to help their understanding (*see Box on the next page*). However, I suspect it is not a method that would suit everyone.

Breaking Up the Decision Problem – Incremental Approach

In the News Blog concerning the information paradox,[2] I mentioned certain processes to mitigate the problem. Richard Martin and colleagues [14] suggest, first, that information should be provided in aliquots – do not just dump all the information in its entirety. Also, they advise that the pace of information delivery (and perhaps even the amount of information delivered) should be adjusted according to the patient's ability to assimilate the material. There are risks here that the clinician will not get it right – judgement is called for. But herein lies the art of practice, making judgments about how much

Box

A patient was referred to my obstetric clinic because she wanted a second opinion. She had a condition called kyphoscoliosis where her upper spine was severely bent. Such an anomaly can put pressure on the lungs and hence the right side of the heart. Since the volume of blood passing through the heart increases dramatically (~40%) in pregnancy, a patient with kyphoscoliosis can come to harm. My patient's general physician had told her "*that she should not contemplate pregnancy*". Having formed a rapport with the patient, we agreed that the nub of the problem concerned her risk of dying as a result of pregnancy. I then asked her to think of the risk that she would be prepared to run to have a child. I asked her to return in a few weeks, during which I asked her physician what he thought the risk of her dying from pregnancy might be. "*As much as 2%*", he said. When she came back, I told her this news. Her trade-off figure had been 10%. She was overjoyed and a year or so later I delivered her baby safely.

information can be delivered and at what pace. It is here that I think clinicians and members of the public can fruitfully work together to improve practice and where drama may have a role in improving flexible communication skills. This is an area where we plan further research.

People with Low Health Literacy

In a review of this topic, Muscat, et al.[15] considered mainly use of language to accommodate those with low reading age and involving consumers/public in the design of the decision aid. I could find little evidence on methods to prevent information overload specifically in people with low health literacy. However, some of the general methods mentioned above may help: tailoring the amount of information delivered at any one time; providing more time/sessions to support the decision maker; and involving family/friends in the consultation. It seems right to ask the person (as you proceed) whether or not they want more information and providing plenty of space and opportunity for them to express opinions and ask questions. Where time is a constraint, decision aids delivered on the computer, can be recommended for use between sessions. The use of computers to capture the medical history can release clinical time for more complex consultation tasks.[16]

Personal Stories

Some people argue that providing personal stories can augment the more abstract presentation of data thereby clarifying issues for the decision maker. This topic is reviewed by Shaffer, et al.[17] At first assessment, providing accounts of other people's 'lived experience' might seem helpful. However, including narratives of individual choices in decision aids is rightly contentious. They improve knowledge in some studies (compared to aids with no narrative). However, they can result in slanted recall. The literature shows very varied responses in terms of how they affect decisions taken, decisional conflict and knowledge acquired. My concern arises from the fact that they can be very persuasive. It follows that unless a narrative pointing one way can be accurately titrated against a narrative pointing in the opposite direction, then they are directive and hence must undermine the very reason for use of a clinical decision aid. Thus, when we are trying to persuade people to live healthy lives (stop smoking) use narratives all you want. However, be circumspect in the use of narrative when you are offering choice – planned home versus facility births, for example. Stories can easily degrade non-directive counselling into persuasion.

Overarching Principle

It goes without saying that presenting choice cannot be hurried or done in a mechanical, dispassionate way. The clinician must first earn the patient's trust and display empathy throughout – a point that comes out very strongly in the Spiegelhalter review cited above.[8] Chat to your patient about their immediate family. Ask them how they are feeling. Being able to express one's emotion is not only psychotropic – it also helps clear the mind for the decision task at hand. The neurophysiology shows that a person needs emotion – without it you just cannot make a decision. However, too much emotion and the brain becomes overwhelmed and reasoning is crowded out. Indeed, supporting non-directive decision making blends art and science.

In conclusion I hope you found this romp through decision aid design interesting. In this article I concentrated mostly on the decision aid artefact. In a forthcoming blog I shall discuss the implementation of decision aids given that, as stated, they do not exist in isolation of the service itself.

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West Midlands Public Health Alliance Conference

Prof Kate Jolly, ARC WM Public Health theme co-lead

ARC West Midlands recently co-sponsored an in-person conference for public health practitioners across the region on the topic of '**Weathering Uncertainty through Innovation**' on 16th October 2024. The conference brought together over 200 West-Midlands public health professionals from local authorities, trusts, Integrated Care Boards, the Office of Health Innovation and Disparities (OHID), UK Health Security Agency (UKHSA), West Midlands Combined Authority and NHS England.

Mike Wade, *Regional Director of Public Health*, and Allison Duggal, *Director of Public Health at Coventry City Council*, set the scene for 'Weathering Uncertainty through Innovation', while keynote presentations from Professor Kevin Fenton, *President of the faculty of Public Health*, and Sarah Price, *Director of Public Health, NHS England,* highlighted the challenges faced in improving the public's health and offered some ways forward. The consistency of the challenges across the speakers was notable:

- Ageing population.
- Huge disparity between most and least deprived in years of good health (51.9 versus 70.7 years).
- Years of austerity with a significant reduction in council spend per person (most pronounced in the most deprived areas).

Sarah Price summarised the challenge as needing to: (i) reduce morbidity and mortality in working age - particularly in more deprived groups; and (ii) reduce the burden of disease in older adults. We were reminded that return on investment for evidence-based interventions for the prevention and treatment of diabetes, cardiovascular and respiratory diseases occur within three years through reducing health inequalities, reduction in excess mortality, and reducing admission rates.

Kate Jolly, co-lead of the ARC-WM Public Health theme, updated the conference on the research undertaken by ARC WM and described the wide range of NIHR-funded infrastructure that is relevant for public health professionals in the West Midlands and nationally.

The day provided an opportunity to share some of the public health projects undertaken with our partner local authorities and contribute to themed workshops. Workshops addressed healthy early years, healthy adulthood, healthy ageing, healthy environment, public mental health and wellbeing, and public health workforce. ARC WM contributions included Beck Taylor co-leading a workshop on Influencing drivers of neonatal and infant mortality at system level. Laura Kudrna co-led a workshop on healthy workplaces.

Potential solutions to the above challenges were reflected in workshop discussions, such as tackling inequalities through careful tailoring of workplace for support in local government workplace health programmes, and investment in work and health coaches that can help to tackle barriers to employment.

An Applied Example of How Patient and Public Involvement and Engagement Improved Study Documents and Recruitment in NIHR Midlands PSRC

Dr Justin Aunger (Research Fellow – Cross-cutting Theme);
Dr. Magdalena Skrybant (Lead for PPIE)

Background on Cross-Cutting Theme PPIE

The Midlands PSRC is comprised of acute, maternal, and cross-cutting themes. The cross-cutting theme is currently focused on developing a research stream focused on improving safety culture, and on improving care pathways in respiratory medicine. Magdalena Skrybant, lead for PPIE at the Midlands PSRC, has worked diligently to set up a PPIE group for the cross-cutting theme and has co-developed a wider PPIE strategy with these contributors. Now, we are actively engaging this group to assist in co-developing various emerging projects within the cross-cutting theme.

Engaging Our PPIE Group

As an example of our recent engagement efforts, we engaged with our cross-cutting theme groups to enhance patient-facing documents for a study we are developing. This study will involve interviews with patients who have small lumps in the lungs called pulmonary nodules. These nodules can potentially lead to cancer, and we want to understand how patients with them have been cared for and how this care could be improved. See our previous blog "Setting initial research directions for the core research theme of the PSRC" for more details. Our process for engaging with PPI members was as follows:

1. We sent the patient information sheet, invitation letter, consent form, and patient interview topic guide via email a week in advance to give our contributors time to read them over and form an opinion.
2. During the meeting, we presented the documents live and went through them in a guided manner to gain any feedback.
3. On some of the documents, we were able to make 'live changes' so that the contributors could see the difference they were making in real time.
4. After the meeting concluded, we provided the contributors with a summary of actions that would be taken to improve all the documents.
5. As soon as the documents were revised, we sent them back to the contributors for feedback to ensure that we captured all their desired changes.

A Worked Example

As an example, our patient information sheet underwent significant revisions. The contributors were very forthcoming when it came to improvements we could make. Main points of feedback were to improve how eye catching the document was, and to make the study team more approachable by including photos of the study team. Examples to improve engagement included: (1) adding photos; and (2) using more 'active' language (e.g. "*We will do*

X", rather than "*This study will do X*"). Figure 1 provides an example of the scope of changes (in red text) made to this document as a result of this meeting.

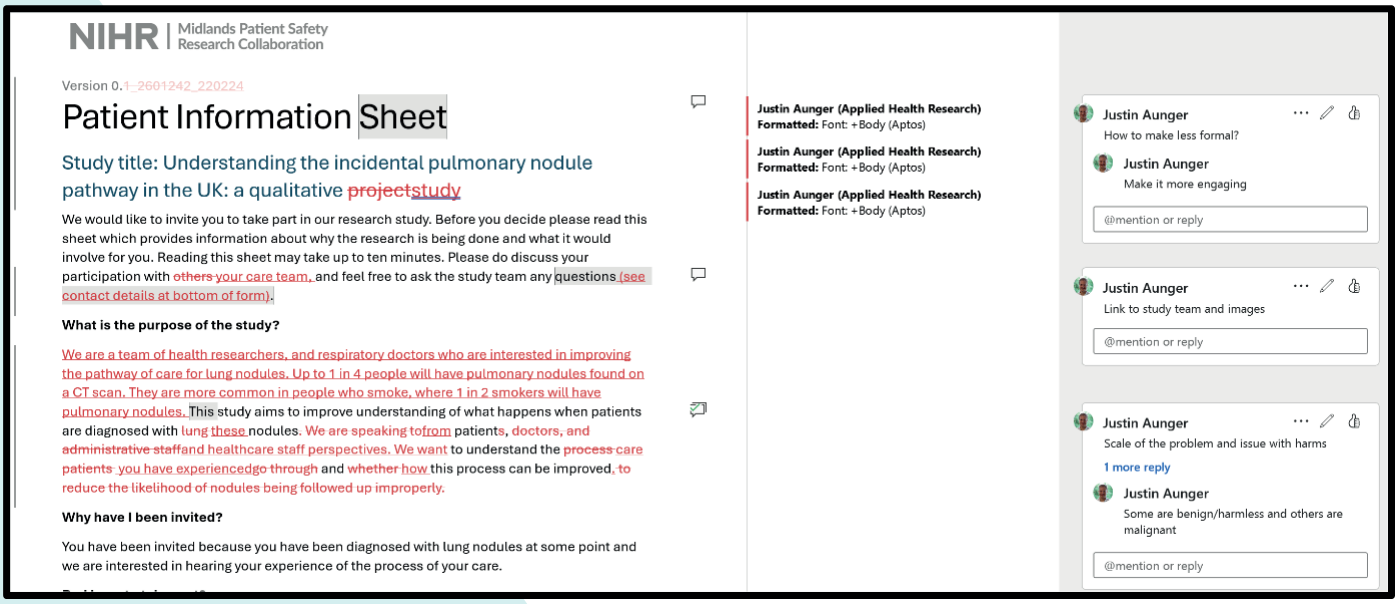

Figure 1. Example suggested changes to Participant Information Sheet.

We have provided an example in Figure 2 below to highlight how the same section looked before PPIE input versus after. Contributors highlighted that:

- this section was overly wordy and could be broken up into smaller chunks to improve readability (we used the bullet points to accomplish this)
- a visual aid would enhance clarity of this section in terms of what participants will actually do, and so we created a figure to depict this.

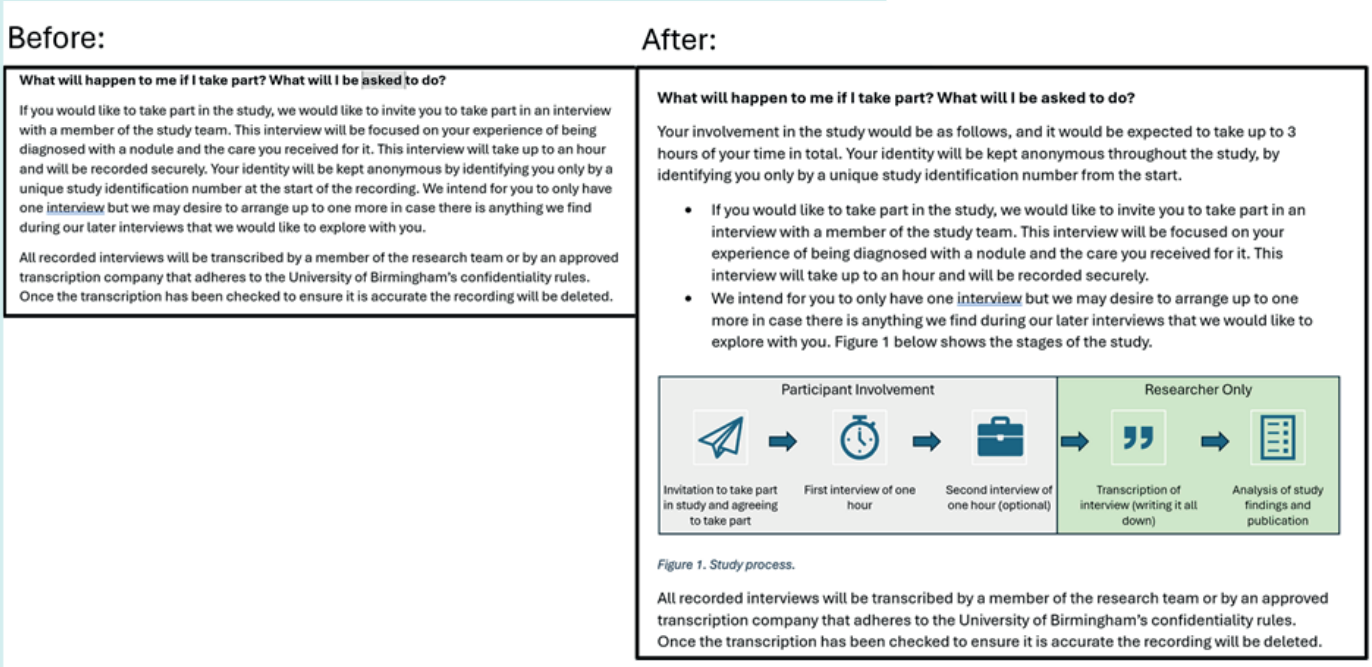

Figure 2. Example section before and after PPIE input.

These examples highlight how a relatively small investment into PPIE can have large pay-off. We think these changes will be likely to improve participant recruitment for the study.

Next Steps

We are continuing to work on a range of initiatives to improve how we conduct PPIE in the PSRC in line with our PPIE strategy. We aim to collaborate across other 'One NIHR' programmes of work such as ARC WM to achieve this.

Current initiatives we are pursuing include:

- Developing a PPIE capture form for contributors to fill out at the end of activities to ensure their voices and feedback are captured.
- Expanding our cross-cutting theme group of contributors by developing an advert for this purpose.
- Developing role descriptions to enhance clarity of roles across PPIE opportunities.

In the coming years, we hope to provide you with further examples of how PPIE has made a difference in our work.

ARC WM Quiz

Dracunculiasis (or Guinea-worm disease) is a near-eradicated parasitic disease, but what animal helps spread it in humans?

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

Answer to previous quiz: The anti-malarial medication that was first extracted from the bark of cinchona tree in 1820 was **Quinine**.

Congratulations to Alan Hargreaves and Mark Gabbay who were first to answer.

World Patient Safety Day 2024

Sopna Choudhury, Research Programme Manager (Midlands PSRC)

This year, the World Health Organization's World Patient Safety Day, celebrated annually on 17th September, focused on the theme "*Improving Diagnosis for Patient Safety*", with the slogan "*Get it right, make it safe!*" This theme presented an important opportunity to raise public awareness and foster collaboration between patients, healthcare workers, policymakers, and leaders to improve diagnostic processes and patient safety overall.

Diagnostic errors can have serious consequences for patient safety and healthcare outcomes. Timely and accurate diagnoses are critical to providing the right treatment, whereas delays or misdiagnoses can lead to inappropriate care, worsened health conditions, and even preventable deaths. By emphasising the need for enhanced diagnostic procedures, the theme encourages healthcare professionals and policymakers to develop better tools, practices, and training. It also promotes active patient engagement, empowering individuals to take a proactive role in their own care.

In alignment with this theme, the Midlands PSRC held two successful events to celebrate World Patient Safety Day:

1. **In-person event** at the atrium of the Queen Elizabeth Hospital Birmingham, featuring stands from NIHR Midlands PSRC, NIHR ARC West Midlands, the NIHR HealthTech Research Centre in Devices, Digital and Robotics, and the UHB Trust Patient Safety Team. This event attracted both patients and healthcare providers.
2. **Online event**, attended by 95 participants, which included:
    - Reflections from *Baroness Gillian Merron*, Minister for Patient Safety, Women's Health, and Mental Health.
    - A talk on **AI in diagnostics** by *Professor Brendan Delaney*, Chair in Medical Informatics at Imperial College London.
    - A discussion on **primary care diagnosis** by *Professor Willie Hamilton*, University of Exeter.
    - A presentation by *Andrea Brady*, mother of Jessica Brady, on **Jessica Brady and the CEDAR Trust**.
    - Insights into the **Shared Safety Action Plan (SSNAP)** by *Pam Essler*, a Lay Leader supporting PPIE in SSNAP development.

These events provided a platform for key stakeholders to engage in critical discussions and promote improvements in diagnostic accuracy, ultimately supporting the goal of safer and higher-quality healthcare.

Effect of 'Sugar Tax' on American Consumer Habits

Peter Chilton, Research Fellow

Much has been written about the impact and effectiveness of 'sugar taxes', following various government bodies putting them into policy to combat issues such as obesity and type 2 diabetes. A recent article in *Health Economics* looked at 400 households across four US cities that had recently implemented taxes on various sweetened drinks. [1] They were particularly interested in the effect the taxes had on lower-income households as, on average, they have a higher consumption of sweetened drinks.

When compared to households in three comparison cities, data showed that households subject to taxes purchased fewer sweetened drinks, with the greatest difference seen in lower-income households – almost a 50% reduction in purchases. In comparison, higher-income households showed an 18% reduction. Further, there was no evidence of households shopping in different areas to avoid the effect of the taxes on their purchases. These findings suggest a hopeful route that similar taxes can have an ongoing effect on reducing health inequalities and improving the health of the general population.

Reference:

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NIHR Pre-Application Support Funding

The NIHR Applied Research Collaboration West Midlands is excited to announce a Pre-Application Support Fund. The fund will provide extra support to individuals to enhance their chances of making a successful application to an NIHR career development scheme in the future. This complements the national NIHR Pre-Application Support Fund.

The ARC West Midlands Pre-Application Support Fund is open until Monday 4th December. Full details, including an application form and guidance notes can be found at: www.arc-wm.nihr.ac.uk/training-capacity-and-development/nihr-pre-application-support-funding/

Eligibility

You must be able to undertake and complete your award by 31st March 2025.

We are particularly keen to support individuals from groups and professions under-represented in NIHR. This includes, but is not limited to:

- regulated healthcare professionals (nurses, midwives, allied health professionals, pharmacists and healthcare scientists)
- social work and public health professionals
- researchers in methodology
- researchers based in local authority settings

Priority will be given to those at the early stages of an academic career, and to those working in the West Midlands region.

Support

Each award includes funding (up to a maximum of £18,000) to:

- buy out of time on current salary
- patient and public involvement and engagement costs
- conference and training costs
- supervisor costs
- a training needs analysis
- sign-posting to an extended supervisory team and mentorship
- sign-posting to institutional resources, including inclusive staff networks
- bespoke training and supervision as needed required
- pitch-to-peer sessions
- critical appraisal of fellowship applications and mock interview preparation

Latest National NIHR ARC Newsletters

The latest issues of the NIHR ARCs Newsletter are now available at: http://eepurl.com/ioyF8c and http://eepurl.com/i2l8-Q. These issues include inequalities faced by women in the North of England; the largest ever study on British South Asian maternal mental health; and regional inequalities in community resilience.

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

European Research & Evaluation Award

Robin Miller & Caroline Jackson from our Social Care theme were part of the team that recently won the *Research & Evaluation* category at the prestigious **2024 European Social Services Awards**. Hosted by the European Social Network, the awards recognise outstanding achievements in social services and highlight successful new approaches.

The winning project was a collaboration with the *National Development Team for Inclusion* (a national social care improvement body), in relation to their Community Led Support Programme. Robin led an inter-university team (including ARC KSS and ARC SL) funded by the NIHR National Priorities Programme Adult Social Care & Social Work, and were supported by a panel of people with lived experience of social care co-ordinated by Caroline.

For more details of the project, please see: Research report into Community Led Support - NDTi.

See the University of Birmingham press release for further information.

Importance of Assessment in Maternity Triage

The Care Quality Commission (CQC) recently published a national review of maternity services for 2022-2024, which highlighted the importance of maternity triage and recommended the **Birmingham Symptom-specific Obstetric Triage System (BSOTS)** to improve safety, a system developed with the Maternity theme at ARC West Midlands.

The importance of patients requiring emergency maternity services receiving care dependant on their level of need, is discussed by Prof Sara Kenyon, theme lead, at: www.birmingham.ac.uk/news/2024/safe-and-timely-assessment-in-maternity-triage-is-vital-to-improve-safety.

Black Talent Award Recipient

Congratulations to Yemisi Takwoingi, Professor of Test Evaluation and Evidence Synthesis in the School of Health Sciences, who recently won the **Black Talent Award** for Public Sector/Services, NHS and Education.

Yemisi was recognised for her commitment to promoting health and social care research career pathways for those who are often underrepresented - including through the NIHR Race Equality and Diversity in Careers Incubator, which formally launched earlier this year.

Job Opportunity: Strategic Improvement Coach

The Social Care theme at ARC West Midlands, led by Prof Robin Miller, are looking to employ a part-time Strategic Improvement Coach to lead a 12 month change project to facilitate engagement in research by occupational therapists, based within the IMPACT (Improving Adult Care Together) centre.

Deadline for applications: **25 November 2024**.

For further information, and to apply, please visit: www.jobs.ac.uk/job/DKF879/strategic-improvement-coach

National Maternity Safety Conference Posters

Researchers from the Maternity theme of ARC WM had three posters displayed at the recent *National Maternity Safety Conference* on 26th September, one of which was awarded the runner-up *best poster* prize.

The poster was titled '*Regional Implementation of Strategies to Improve Clinical Escalation in Intrapartum Care: A Mixed Methods Evaluation*' by Nimarta Dharni, Fiona Cross-Sudworth and Sara Kenyon (*right poster in photo below*).

ARC WM Seminar Series

Upcoming dates for the continuing ARC WM seminar series are below:

- 3 December 2024, 12-1pm "*Admissions for Malnutrition and Vitamin Deficiencies in England 2001-2021*" presented by Katharine Reeves.

The series will continue into 2025 in a joint partnership with the NIHR Midlands PSRC, running approximately every six weeks, starting 15 January 2025.

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

NIHR Doctoral Local Authority Fellowship Application

The Doctoral Local Authority Fellowship (DLAF) scheme funds individuals based within local authorities and supporting services to undertake a PhD and professional development within their current setting, but on sabbatical from their existing role.

For further information, please visit: nihr.ac.uk/funding/nihr-doctoral-local-authority-fellowships/36553. Deadline for submission is **5 December 2024**.

Recent Publications

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