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Comparing Durations Between Different Milestones on the Pathway from Symptom to Treatment

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

Cancer survival rates are heavily dependent on stage at presentation. In turn, stage at presentation is influenced by delay in treatment following first symptoms. The symptom to treatment delay can be divided into two major stages – from first symptom to presentation at the health service, and from presentation to treatment.

Measuring these delays prospectively is difficult or impossible since a study population cannot be identified at the time of symptom recognition. Therefore, the literature on delay is based on retrospective studies, where people with cancer are interviewed to reconstruct their journey from first symptom to diagnosis (or treatment). Guidelines for the conduct of these studies have been promulgated through the Aarhus checklist. [1]

Memory is, of course, fallible. It is, therefore, inherent in the above retrospective method that there will be (considerable) measurement error. Recall can be improved by asking the responder to relate medical events to personal or public events to which a firm date can be ascribed – a wedding or religious holiday, for example. The impacts of measurement error can also be mitigated by selecting large samples. The purpose of this article, however, is to draw attention to another problem: that recall may not just vary at random over the recall period, but may vary systematically. That is to say, there may be a systematic tendency to over- or under-estimate time differences as they recede from the present time. Indeed, there is evidence for such a systematic bias in perception. Memory is 'telescopic', such that more distant events appear more recent than the actual occurrence, relative to more recent events.[2]

Previous research into median time delays between events finds that median delay periods from first presentation to treatment are longer than the delay periods from first symptom to presentation.[3] [4] However, if more distant events are perceived, relative to more recent events, as occurring later than they actually occurred, then the above findings might

exaggerate the duration of the presentation to treatment epoch, relative to the symptom to presentation epoch.

Is it possible, in the absence of independent objective observations, to design a method to empirically measure (and therefore correct for) 'telescoping', with respect to cancer delay interval periods? We propose a method that might support the above conjuncture – that more distant events on the cancer pathway appear more recent on average. In any database of time intervals collected using the Aarhus retrospective method, there will be people who had a short and long 'second delay', i.e. the delay from presentation to treatment. Then, under the conjuncture, the first delay should be less 'telescoped' in those with short second delays than in those with long second delays. This should show up as a difference in the difference between first and second delays according to the duration of the first delay. We therefore propose to examine this difference in the difference between second and first delays. We expect to find that shorter second delays are associated with a difference in the differences. The greater the inverse correlation between these variables, the greater the degree of telescoping in cancer delay research.

There is, of course, an assumption behind this interpretation. The proposed method assumes that there is no correlation between the lengths of the two delay periods – i.e., people with longer time second delays do not tend to have true longer (or shorter) first delays. However, this assumption might not hold. For example, deprived people with low health literacy may both fail to recognise symptoms and then be treated differently in the service. It would, however, be possible to adjust for this bias in data-sets that recorded the necessary variables. Also, if there is no evidence of telescoping, then we can be somewhat reassured regarding retrospective comparisons of different journey stages on the pathway from first symptom to treatment.

References:

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Describing a Utility to the State of Death: Pervasive Practice in Health Economics, but a Poor Idea

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

In a previous news blog, I argued that the state of being dead should not come into a health utility analysis.[1] Even if the disutility is discounted, I argued that this is an erroneous practice. Here, I build on this argument: first, with arguments against the practice, some of which summarise my previous argument; then a counter-argument, based on the idea of an intrinsic value of an un-lived life. Finally, I will counter the counter-argument.

Arguments against projecting a utility value of zero throughout an individual's remaining life in an economic model:

1. **One, the axiomatic argument**. As argued previously, it is automatically wrong to ascribe a value of disutility to somebody who is dead because there is no disutility to be experienced. There is a disutility contingent on facing death and this should be accounted for. But not so the utility of the dead state itself. Describing such a utility to a health economic decision is a fallacy that arises from using methods developed for an individual person concerning their own treatment, not for use in aggregate decision-making. The axiomatic error that health economists make here is to conflate a person's trade-off while they are alive with the disutility of the dead state, relative to other states the person might be in where they are not dead. The issue is compounded by summing the disutility of the dead state over each remaining year of life.
2. **Two, the lived experience argument**. While a person cannot experience a loss of utility while dead, they certainly can while alive. Therefore, the disutility of the state in which a person is moving to death should certainly include the dread of their impending death. In fact, in so far as death can be averted at a younger age, the dread of not being rescued when such rescue is possible, should also be factored into the calculus. But it is lazy to use the utility of the state dead as a surrogate for these factors.
3. **Three, the spill-over argument**. Currently, the dead person suffers a disutility of one (utility of zero), while members of the family do not lose any utility at all. Consider the health economics of infertility treatment. Here the beneficiaries must include all those who gain utility –the index woman may not even be the person who is treated, nevermind the only beneficiary. The same applies when someone is dying and persists after they have died. It should be accounted for, insofar as it might not be encountered (as in the case of a child), or be attenuated (as in the case of a death deferred to an extreme age).

The **counter argument** is that there is indeed a value in human life, even if the disutility is not experienced. This whole argument turns on the fact that if the life could be created or preserved, then it would still experience a utility. That is to say, it is the utility forgone that must be included in the model. Indeed, this is Parfit's 'repugnant conclusion' argument mentioned previously in your news blog.

Countering the Counter Argument

It is more coherent to think about decision outcomes in terms of disutility than utility. Failure to do that might leave one in a blind alley, and the above conclusion is indeed repugnant. The repugnant conclusion rubric is at variance with contraception or, indeed, any failure to take advantage of a reproductive option. Once one thinks in terms of disutility, then the argument becomes clear. The optimal decision is simply the one with the least disutility for people who exist or may exist in the future. The only argument left is the population disutility that might be avoided by productivity that may be realised when death of a working age person is avoided –but that is a topic for another day!

To conclude, a new model is needed that focuses only on the disutility of people who are living, including those who are dying, and completely excludes a utility that is not experienced.

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Quiz

Born on 22 August 1867, Maximilian Oskar Bircher-Benner was a Swiss physician who developed what popular meal to improve health of his patients?

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

Answer to previous quiz: The mosquito that has recently evolved in the horn of Africa, and which bites in day time, lives mostly in cities, and is resistant to insecticides is ***Anopheles stephensi***. Due to this mosquito, cases of malaria have soared in Djibouti and Ethiopia.

Congratulations to those who were first to answer correctly.

Comparing Findings from Step-Wedge Trials with Nested Parallel Designs

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

It is sometimes argued that step-wedge cluster designs are not as pure as parallel cluster RCTs with before and after measurements. This 'impurity' arises because it is necessary to allow for calendar time in a step-wedge design. This, of course, is a non-experimental manoeuvre with a theoretical risk of introducing bias. But how important is this factor really? In this short article, I propose a study to shed light on the above question.

It so happens that it is possible to find parallel, cluster studies with baseline observations *within* step-wedge designs. How this is possible is shown diagrammatically in the Figure.

This means that a type of meta-analytic study is possible. That is to say, it is possible to compare the findings from step-wedge trials with the findings from the parallel designs that are nested within them.

To do this, it would be necessary to take a population or a random selection of step-wedge designs to form the sample for investigation. The probability that the results are alike to a specified, but narrow, degree could then be tested statistically.

The sample of step-wedge studies would need to be those with a complete design, meaning that all the steps contributed to the observations. One could place other stipulations, such as a minimum of eight steps with eight observations at each step.

I am writing this news blog first, to see whether readers think such a study is possible in principle; second, to find out whether it has been tried before; and third, to elicit ideas on the search strategy, inclusion, criteria, and subsequent analysis.

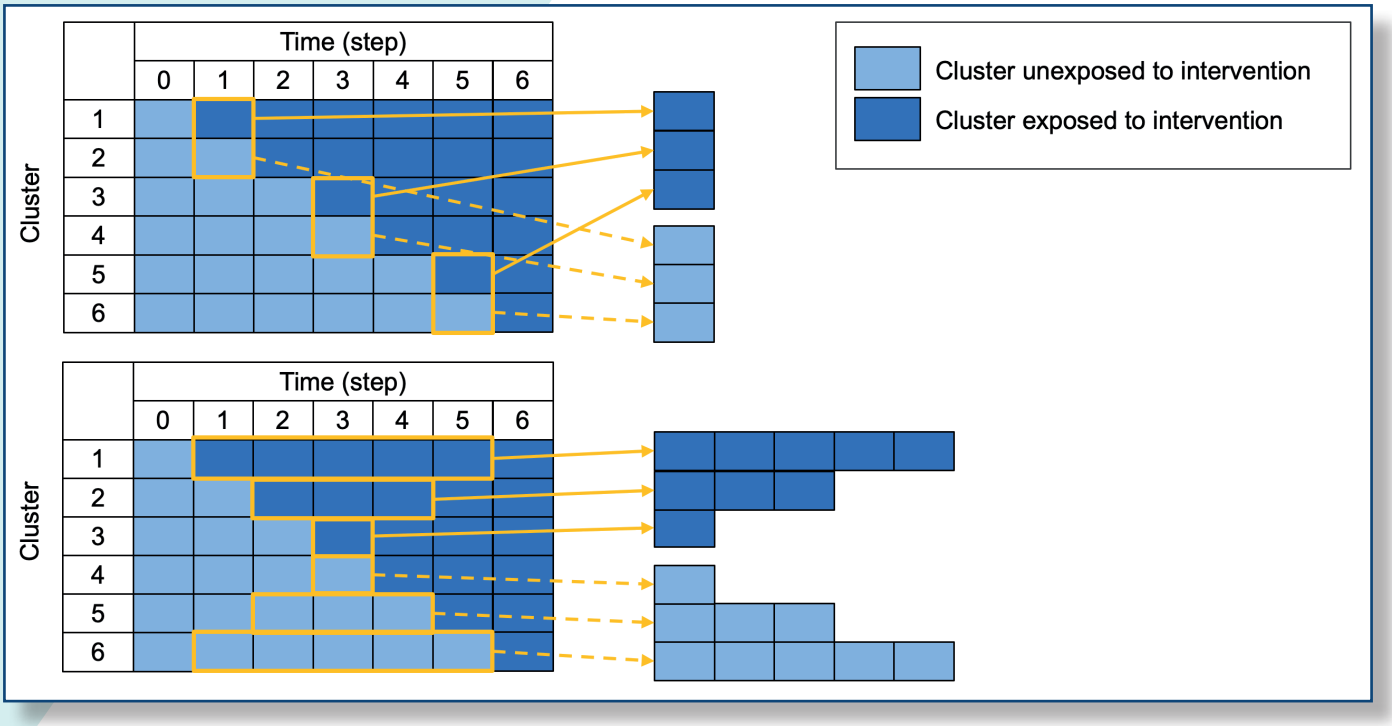

Figure: Parallel cluster RCTs nested within step-wedge designs (after Hemming, et al. BMJ. 2015; 350: h391.)

Unprofessional Behaviour and the Hidden Risks to Patient Safety

Dr Justin Aunger, Research Fellow in Midlands PSRC

How do day-to-day tensions between healthcare staff impact patient care? A recent paper published in the International Journal for Quality in Health Care sheds new light on this important question.[1] Titled "*Co-worker unprofessional behaviour and patient safety risks: an analysis of co-worker reports across eight Australian hospitals*", the study provides a robust analysis of how poor professional conduct among staff links to threats to patient safety.

The study, led by Ryan D. McMullan and colleagues at Macquarie University and the University of South Australia, analysed over 1,300 "feedback for reflection" submissions – anonymous reports from hospital staff describing unprofessional behaviours they had witnessed among their colleagues, submitted as part of the Ethos professionalism intervention. The data spanned eight Australian hospitals and included a wide range of clinical roles and specialties.

A concerning finding: almost a third (30.2%) of these reports explicitly mentioned a potential risk to patient safety.

By applying both logistic regression and thematic analysis, the researchers uncovered patterns in which behaviours were most likely to be associated with safety risks. Common behaviours included refusal to assist colleagues, poor communication, incivility, and undermining. Crucially, these behaviours weren't just upsetting – they often disrupted workflows, delayed care, and increased the risk of clinical errors.

To categorise the risks, the team used the World Health Organization's International Classification for Patient Safety (ICPS) framework.[2] The WHO ICPS was developed to support consistent reporting and learning from patient safety events across different healthcare systems. It defines key concepts (such as "harm," "incident," "near miss") and categorises types of safety risks, such as clinical process issues, communication failures, medication errors, and system-level hazards. The most frequently described safety risks involved delays in care or treatment, failures in coordination (e.g., poor handovers), and risks to medication safety.

While most NHS staff will be familiar with the challenges of working in high-pressure environments, this study puts evidence behind a long-suspected truth: unprofessional interactions between staff do not remain "*just between them.*" They ripple outward to affect team functioning, clinical decision-making, and ultimately patient outcomes. Importantly, the analysis also shows that behaviours often seen as more mild can actually have severe impacts on team cohesion and communication, which are critical pillars of safety culture.[3]

Why it matters for the UK's NHS

Although the study was conducted in Australia, it also has relevance to the UK context where 20-25% of staff report bullying, harassment and abuse each year – and where the number experiencing broader incivility is likely much higher.[4] Initiatives such as the NHS Civility Saves Lives campaign and the recent focus on staff experience in the NHS Long Term Workforce Plan have underlined how important

team culture is to safe, high-quality care. This is also reflected in the NIHR patient safety research priority to improve safety culture.

This paper provides strong empirical backing for interventions aimed at fostering respectful, supportive working environments. It suggests that reporting systems, when designed to capture patterns and themes (rather than just serious incidents), can reveal valuable insights about latent risks in the system.

This study was made possible by the Ethos intervention, an Australian peer reporting and feedback intervention that not only supports professional accountability but also generates rich, structured data about workplace behaviour and its effects on care – similar to other US-based interventions such as those developed at the Vanderbilt Medical Center.[5] The paper states that "*users who complete a feedback for reflection submission are also asked: 'Do you think this event put PATIENT safety at risk?' and 'Do you think this event put STAFF safety at risk?' If 'Yes', users are asked to briefly describe the risk.*" It is possible that this may 'cue' respondents to think more actively about patient safety risks and bias them towards saying yes overall. However, this would not affect which behaviours are more associated with those risks.

Currently, no equivalent infrastructure exists in the UK to systematically capture and analyse this kind of frontline intelligence at scale. Thus, as the NHS continues to focus on both patient safety and staff wellbeing, building similar data systems could be an important and effective step towards understanding the impact of staff behaviours on patient safety.

Take Home Messages:

- 30% of reports about co-worker unprofessionalism included a potential patient safety risk.
- Refusal to assist, rudeness, and communication breakdowns were most strongly associated with safety concerns.
- Patient safety risks ranged from delayed care to medication errors and failures in coordination.
- Understanding and addressing unprofessional behaviours – even those previously seen as mild - should be seen as a core component of patient safety work.

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National Investigation into Maternity Units

Dr Hsu Chong, Consultant in Maternal & Foetal Medicine

Wes Streeting (*Secretary of State for Health and Social Care of the United Kingdom*) has recently announced a national investigation into all maternity units and this is welcome news. This is in part because we need to evaluate variations in care delivery across the country in a structured way, and not only when things go wrong.

Dr Edile Murdoch (*a consultant neonatologist in Edinburgh*) has devised a mechanism by which this could be achieved – MOSS, the Maternity Outcome Signal System. MOSS is a digital system that is purportedly to be introduced to all maternity services by November 2025. Its purpose is to highlight "*potential safety concerns, and support rapid, national action*".

This reminds me of an excellent movie from the early 2000s, "*Minority Report*" (starring Tom Cruise and Samantha Morton to name a few). In this movie, Samantha Morton is part of a trio of oracles that can foresee the future. Tom Cruise stars as the protagonist who prevents adverse outcomes based on this information.

Digital systems that can create a warning signal sounds great – but staffing, education, processes and policies still need to be in place to pre-empt the harm. I can see the raising of potential safety concern and transparency in reporting as a highly achievable objective, but "*rapid national action*" less so. It is also unclear if patients can input into MOSS. Escalation and action appear to be locally owned, i.e. by the maternity unit. This could mean that variation in care provision could still occur.

Electronic maternity notes are used widely during pregnancy and could potentially improve safety. In the Midlands PSRC Maternal Health theme we seek to undertake a qualitative study involving patients and clinicians to understand how to optimise its use. Understanding its use could help us navigate a better way of standardising care provision, create decision support or prompts, and perhaps even evaluate deviations from guidelines. Our protocol is being reviewed by ethics so watch this space for updates and how to participate!

The Impact of Policy and External Events on Elective Surgeries in the NHS

Peter Chilton, Research Fellow ARC WM

New research from NIHR ARC West Midlands reveals how a 2002 NHS policy, the 2008 recession, and the COVID-19 pandemic have influenced cancelled elective operations and breaches of the 28-day re-admission standard in England.[1] This comprehensive study, spanning three decades that saw elective admissions almost double to 2 million per quarter, offers valuable insights into the resilience of the UK health service.

The study shows that a policy introducing financial penalties for hospitals that failed to operate on a patient within 28 days of a last-minute cancellation was initially highly effective – breaches of this standard dropped rapidly after the policy's implementation and remained at a low level for many years. However, the findings show that this success could not be sustained in the face of significant external pressures. While the 2008 recession did not affect cancellation rates, it did cause an increase in breaches of the 28-day standard. The most dramatic impact was seen during and after the COVID-19 pandemic, when breach rates surged to their highest levels, effectively cancelling out the gains made by the 2002 policy.

Interestingly, there was a profound difference between hospitals with and without accident and emergency (A&E) departments. Hospitals with A&E departments experienced a significantly higher increase in breach rates following the COVID-19 pandemic compared to those without, suggesting that the added pressure of emergency admissions meant that hospitals were less able to protect beds for elective procedures.

These findings highlight a crucial point, that while policies and targets can be well-intentioned, they are most effective when a health system has sufficient resources and the capacity to manage demand. Without this fundamental resilience, even the best policies can become ineffective, especially in the face of unforeseen crises. This study provides a critical reminder that while targets are important, they must be set within a realistic understanding of the system's capacity.

Reference:

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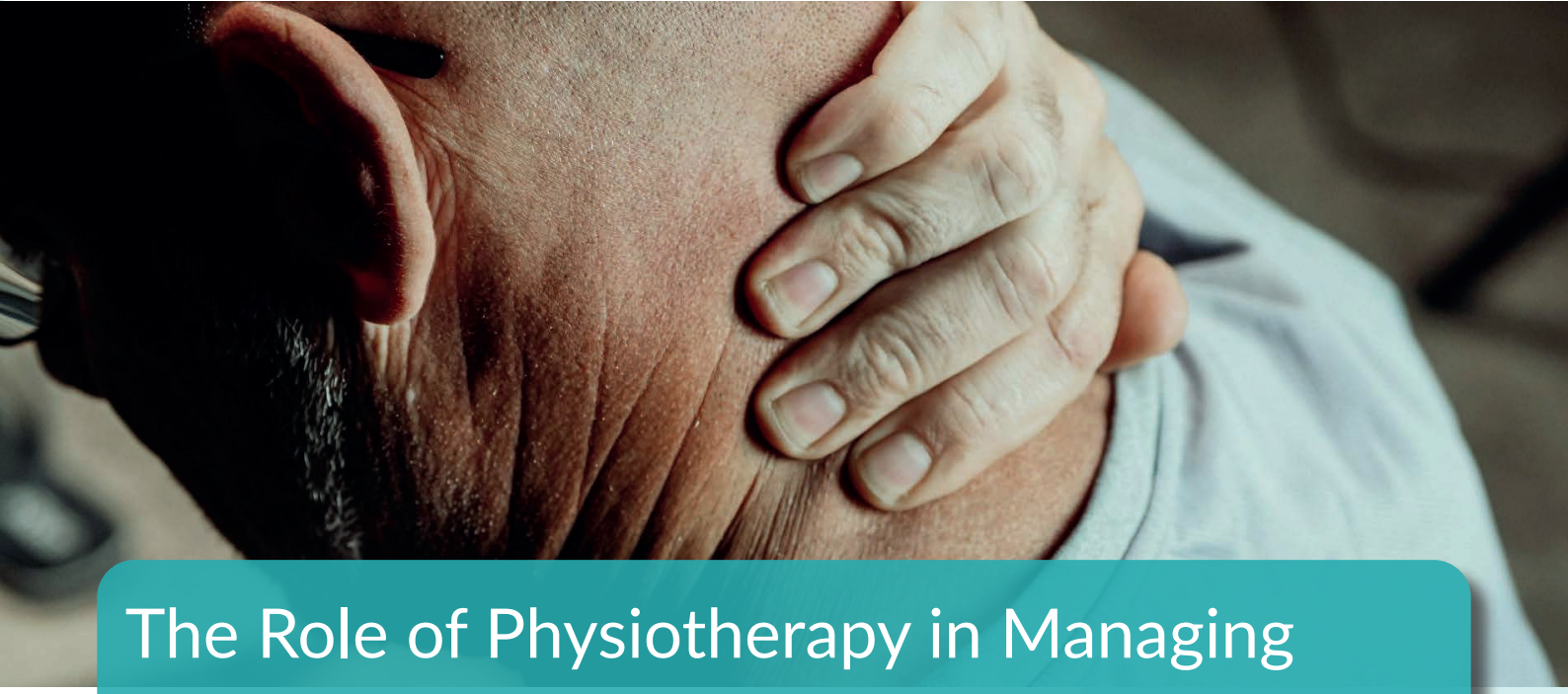

The Role of Physiotherapy in Managing Polymyalgia Rheumatica

Peter Chilton, Research Fellow ARC WM

New research from our Long-term Conditions theme at NIHR ARC WM sheds light on the role of physiotherapy in managing Polymyalgia Rheumatica (PMR), a common inflammatory condition that causes pain and stiffness in older adults. PMR is typically managed with glucocorticoids (a type of corticosteroid), but these can have significant and concerning side effects. There is no current established evidence base for the practice of physiotherapy. This study involved a UK-wide survey of physiotherapists, investigating how they currently manage PMR, and their thoughts on physiotherapy for PMR.

Around 80% of physiotherapists surveyed believed there is a positive role for physiotherapy in treating PMR. While most physiotherapists only see a small number of PMR patients annually – only 5.8% had treated more than ten patients in the previous year – they were still confident in their ability to help.

In terms of treatment, 90% of respondents promote self-management approaches, such as pacing and activity modification. The majority also prescribe exercises to improve movement, muscle strength, and daily function. This is significant because international guidelines for PMR already recommend considering individualised exercises to maintain muscle mass and function, especially for older, more frail patients.

This study highlights the potential value of non-pharmacological approaches to supplement the standard glucocorticoid treatment. The study provides a solid foundation for further research into the effectiveness of physiotherapy for PMR. It also highlights the need for more education about PMR for UK physiotherapists.

Reference:

1. O'Brien AV, Muller S, Liddle J, Thomas MJ, Mallen CD. Physiotherapy for the Management of Polymyalgia Rheumatica: Results From a UK Cross-Sectional Survey. *Musculoskelet Care*. 2025; **23**: e70155.

From PhD to Policy: Reflections from a Fellowship in Parliament with the Health and Social Care Select Committee

Chris Hatton, PhD student in Midlands PSRC Acute Care theme

I currently work as a Clinical Research Fellow and PhD student in the NIHR Midlands Patient Safety Research Collaboration at the University of Birmingham. As part of my PhD, I have recently had the exciting opportunity to undertake a three-month secondment with the Health and Social Care Select Committee in Parliament offered by Midlands Innovation and Midlands Innovation Health (a partnership of the top research intensive universities in the Midlands). The goal of the fellowship was to learn more about the intersection between research and policy, and to understand how research can be used to support policy development. I thoroughly enjoyed my time in Parliament and in this blog, I will outline what I did during the fellowship and highlight some of my broader reflections.

Firstly, a brief introduction to the committee - the Health and Social Care Select Committee is a cross-party committee comprised of 11 Members of Parliament, and their role is to scrutinise the work of government related to health and social care. Supporting this work is an Independent Expert Panel, who were appointed in 2020 to evaluate specific policy areas and provide independent assessments on certain topics. My primary role during this fellowship was to assist with the Independent Expert Panel's evaluation into the state of palliative care in England; an area under the spotlight in recent months given the passage of the Terminally Ill Adults (End of Life) Bill through the House of Commons.

On a day-to-day basis the work I did during the fellowship to assist in this evaluation had remarkable similarities to research. Fundamentally, the process involved gathering, synthesising, and communicating information collected from stakeholders across the palliative care community - skills familiar to all researchers. Before the fellowship, the world of policy had felt somewhat distant from the clinical and research work I had experience of, but familiarity with some technical aspects of the process helped to make the policy world feel more accessible.

Whilst there were similarities, there were also plenty of differences that I had to adapt to. Some

of these differences were related to the place I now worked in, such as meetings in the palace of Westminster. Other differences were related to the process, such as the scope and time scale of work. In research I was more familiar with attempting to answer fairly well defined and comparatively narrow questions. Whereas here the scope was much broader – the state of palliative care services in their entirety. My experiences during the fellowship helped me to appreciate evidence in a broader sense, and to understand how research evidence can be used together with other forms of evidence to inform policy.

I also had opportunities to learn about the broader work of the committee and how it functions to scrutinise the work of government. My time in Parliament coincided with a major health policy announcement - the abolishment of NHS England. I was able to attend a fascinating oral evidence session organised by the committee to hear from the Health Secretary, Chief Medical Officer, and Chief Executive of NHS England about their rationale and provisional plans for this major announcement. During the fellowship I also had the opportunity to attend other events such as the parliamentary launch of the Midlands Health and Care Inequalities Policy Commission.

Overall, this experience helped to de-mystify the world of policy and furthered my understanding of how research can shape policy and real-world decision making. It has helped me to think more about the practical application of the research that I undertake, and has made me more likely to pursue a career that involves both policy and research. I would highly recommend this opportunity to anybody interested in learning more about the intersection of research and policy.

Latest News and Events

ARC WM & Midlands PSRC Seminar Series

Our next seminar will take place on **24 September 2025**, 12-1pm with a presentation by Dr Julia Gauly: '*The usage, experiences and impact of the QI Notify-EmLap mobile app.*'

The QI Notify-EmLap app is a digitally-assisted solution to support clinicians in their emergency laparotomy quality improvement work. You can find out more by clicking here.

Upcoming Seminars:

- 6 November 2025, 10am-11am
- 9 December 2025, 1pm-2pm, Dr Kiyah 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:

- **26 September 2025**, 1pm-2pm, Prof Roman Xu - Hybrid Type 2 Trials and AI for diabetes management.
- 22 October 2025, 1-2pm, Prof Graeme Currie - Organisational factors
- 11 November 2025, 1-2pm, Prof Iestyn Williams - De-implementation
- 2 December 2025, 1-2pm, Prof Robin Miller - Understanding process.

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

Latest National NIHR ARC Newsletter

The August issue of the NIHR ARCs Newsletter is now available at: http://eepurl.com/jke7V-/. It features a report on a study showing giving patients access to their medical notes improves safety and engagement; loneliness leading to earlier care home entry; the impact of early parent-baby communication in neonatal care; and links between children's social care involvement and maternal deaths.

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

Community Study Setup Seminar

The NIHR Research Delivery Network are delivering an online research seminar on 'The Role of RDN Study Support Service in community study setup.' This free event will be held on MS Teams on Thursday 6 November 2025, from 1-2pm.

For more information, and to register, please visit: https://www.ticketsource.co.uk/wm-rrdn/t-dvylzrx

NIHR SSCR Career Development Award

Round 2 of the NIHR School for Social Care Research Career Development Award is now open for applications. This funding provides £20,000 to £75,000 for individuals to undertake personalised training activities and to advance their professional development in social care research.

Applications are invited from anyone committed to building their careers in social care research, including practitioners, researchers at any career stage, and people working in an aligned sector or discipline who want to move into this area of research.

The deadline for applications is **Thursday 25 September 2025**.

For more information, and to apply, please click here.

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://integratedcarefoundation.org/events/icic26-26th-international-conference-on-integrated-care

NIHR West Midlands Health Care Professional Internship Programme

The Research & Innovation Department at the Midlands Partnership University NHS Foundation Trust (MPFT) have been awarded the NIHR West Midlands Health Care Professional Internship Programme. This programme will support 23 interns each year across the West Midlands to work in collaboration with regional NHS Trusts, Higher Education Institutions, and other partners.

Applications for an internship are now open to all registered Health Care Professionals (except Medicine & Dentistry), offering one of four development pathways: stepping into research; growing in research; leadership in research delivery; and clinician/academic leadership in research.

An online information webinar will be held on **Thursday 18 September 2025, 12-1pm** to give an overview of the programme, the pathways, and the support available.

For more information, and to register, please visit: https://bit.ly/MPFTInternshipsWebinar.

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

Babatunde OO, Adetunji O, Alonge I, Owoyemi T, Ayinmode E, Ogunbanjo A, White S, Adebajo AA, Mallen C, Dziedzic K. Process and feasibility of implementing guideline recommendations for the care of osteoarthritis in West Africa. *BMJ Glob Health*. 2025;**10**(6): e018714.

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