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ARC West Midlands &
Midlands PSRC News Blog



The Information Paradox at the Heart of Non-Directive Counselling

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

We may take it as a premise that people should have self-determination – the freedom to make decisions when these do not have material negative effects on others. [Immanuel Kant](#), and the duty to respect people’s autonomy, are typically quoted in this regard. In the context of health care, these principles require that patients are able to choose the type of care they receive according to their preferences. This freedom may be limited by the range of services supported in the health service, and by the person’s ‘*competence*’; their ability to make the decision. In this blog we leave aside the debate about *what* services should be supported in a health system and *how* competence should be adjudicated. Here we consider choice of services that are supported in the health service in the context of people who are competent to make decisions.

Corollaries of the obligation to respect patients’ autonomy are two-fold – patients should be offered choice, and they should be provided with information on which a decision may be based. Indeed, such an obligation is backed in law – recently in the [Montgomery case](#), where the court held that a pregnant woman with a suspected very large baby should have been offered a caesarean-section.

So far, so good. However, this set of principles opens up a second-order problem. This problem concerns how best to inform the decision – more simply, what information should be made available, and how this information should be presented. The first question, *what* information, entails the issue of how much information – this is the (narrow) topic of this blog.

The question could be answered baldly by saying: “*all the information the patient needs to make the decision*” should be made available. But this just kicks the can down the road – what is this information? Here we immediately run into problems. Different patients have different information needs, but there is no way to judge what these needs may be until the information has been shared. That would be fine if the potentially relevant information was limited. But that is seldom the case - a colleague found that the decision regarding caesarean vs vaginal birth turns on over 60 separate and potentially important outcomes/factors. This profusion of potentially relevant factors creates its own set of problems since there are limits to the amount of information the mind can assimilate. In fact, a point is reached where adding more information reduces decision-making capacity. Ironically, beyond this point, the mind will seize on one

(or very few) factor(s) and allow the decision to turn on this narrow range of issues. Beyond a certain point, adding more information actually reduces the number of factors that impact on the decision. According to our NIHR Midlands Patient Safety Research Collaboration (PSRC) collaborator Laura Kudrna, psychologists refer to the mind as a '*cognitive miser*' to explain this phenomenon.[1] Information overload can also exacerbate cognitive biases, such as confirmation bias and recency bias.

There are numerous strategies that may be used to mitigate this 'more is less' problem. The most obvious is to 'layer' the information in a way that allows the patient / decision-maker to determine the range and depth of information provided. Returning to the caesarean vs vaginal birth scenario, the information could be grouped in to four categories, according to factors affecting the baby vs mother over the short vs long-term. Within each category, the information could be layered, offering more or less detail as required. The problem, of course, is that people vary in what they consider most important – as stated above, there is a regress – a person cannot know whether they want certain information until they have received that information.

There is another approach to decision-making, pioneered many decades ago by Pauker and Pauker.[2] This method starts by eliciting the patients' preferences in the form of trade-offs between different outcomes, such as having a baby who has Down's syndrome vs a miscarriage caused by the test to detect Down's syndrome. The Paukers would then reconstruct the decision the patient 'should' make (based on those values/utilities) using expected utility theory. It would be fair to say that such an approach has never caught on. Furthermore, it would be very tedious to repeat trade-off exercises across the full range of valued outcomes that pertain to most decisions – about 60 in the caesarean example above.

The [Maternal Health theme](#) of our NIHR Midlands PSRC is grappling with the above problem, as described in a previous News Blog. [3] We are seeking to link with other research groups around the world who are also looking at potential solutions. Ultimately, we are proposing a set of decision aids that can be used to assist women in making decisions at various points in the maternity pathway; training staff in non-directive counselling; making decision aids available within electronic maternity case-notes; and pointing women and partners to online resources.

The maternity context provides particular challenges for decision support - it must consider outcomes for mother and baby; grapple with very low probabilities of serious outcomes; inform choices that are made over very different time scales (varying from months to a few minutes); and cater for a whole series of choices that may unfold over a single pregnancy. All while catering for people with very different levels of literacy, health literacy and information needs.

We are considering new approaches to the problem that too much information causes cognitive overload yet, when we ask stakeholders which information is most important, they say (nearly) all of it. There is a skill in presenting choice to people about options in their case, and there is also a skill in asking the public about how people should be asked about options for their care. One idea when we do public consultation is to simulate (act out) the consultation between professional and decision-maker. In some enactments we will present all the information designated important and in other enactments we will use a more nuanced approach where agreed key items of a certain type are presented first, and the receiver of the information is then invited to press further. All are given web pages to which they can refer, and all are invited back so that the decision is unhurried. Alternatively, or in addition, we may take a citizen jury approach where alternatives are part of the public panel

who then debate the issues. Finally, the panel might be asked to rank information by salience to the question, and then, after seeing how decisions may actually play out, to choose cut-off points where the person making the decision can be invited to request more information beyond the crucial set. For example, consultees may say that every woman should know that if they select the caesarean section birth mode, then there is an increased risk that they will have a caesarean section in any subsequent pregnancy. Likewise, when considering the long-term effects of a caesarean delivery on the child, rather than run through all possible sequelae the clinician may say something like *'There is also evidence that there may be an increased risk of allergic problems like hay fever'* and then inviting questions or providing further literature.

This is a rather complex proposed research project, but the issue of patient choice is so important that the extra effort and cost seems worth it. At the heart of our approach is recognition of the limitations of simply asking public representatives questions without providing them with some insights into how their responses may play out in practice, and how well-meaning opinions may have consequences that have not been considered. At the end of the day, it is not enough to simply consult the public because the answers will turn on *how* the consultation is conducted – what information is provided, the order in which it is provided, the tone of the delivery, and the context of the exercise. Previous research shows that decisions people make can be strongly influenced by how and what information is presented.[4]

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ARC WM Quiz

What anti-malarial medication was first extracted from the bark of the cinchona tree in 1820?

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

Answer to previous quiz: That the cause of bilharzia was via freshwater snails in contaminated water was first discovered by **Theodor Bilharz** in 1851.

Congratulations to those who answered correctly.





Health Effects of Sunlight: Not Just Vitamin D and Skin Cancer

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

The evidence, taken in the round, suggests that exposure to sunlight causes skin cancer – perhaps most especially basal cell carcinoma and likely malignant melanoma. [1]

But what about the overall effect of ultraviolet light? A recent study in the UK,[2] based on the ~350,000 participants in the UK Biobank study, suggests that exposure to sunlight (sun-bathing and sun beds) is associated with less overall mortality in white people. Reduced deaths include ‘all cancers’ and cardiovascular disease.

White people like the look of tanned skin and get a lift in the process of acquiring a tan. The bronzed ARC WM / Midlands PSRC co-director certainly experiences this feeling. Yet, oral vitamin D has no real health benefit (with or without calcium supplements), according to meta-analysis of RCTs totalling approximately one million participants.[3] This leads me to wonder whether the putative benefits of sunlight might be mediated by a biochemical pathway *other* than vitamin D. The authors

of the Biobank study have made the same suggestion and identified NO (nitric oxide) as a possible mediator between sunlight exposure and health. However, teleology takes me in a different direction. If sunlight is so good for you, why do populations exposed over generations to the most sunlight have dark skin? I can suggest an answer. Maybe dark skin was the default – natural – skin colour. Then, as people migrated to more northern climates, they needed to get rid of the melanin pigment in order to achieve adequate vitamin D levels.

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1. Ananthaswamy HN. [Sunlight and Skin Cancer](#). *J Biomed Biotechnol*. 2001; 1(2): 49.
2. Stevenson AC, Clemens T, Pairo-Castineira E, et al. [Higher Ultraviolet Light Exposure Is Associated With Lower Mortality: An Analysis Of Data From The UK Biobank Cohort Study](#). *Health Place*. 2024; 89.
3. Lilford RJ. [Effects of Vitamin D Supplements](#). *NIHR CLAHRC West Midlands News Blog*. 24 March 2017.



“The Future is Already Here – It’s Just Not Evenly Distributed Yet”

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

Perhaps the above quote from novelist [William Gibson](#) is over-used, but it is certainly true that trends are trends. Some diffuse slowly, while others spread quickly. The new cancer care – with targeted biological agents gradually replacing blunderbuss chemotherapy is a case in point.

A further step in this evolution was published recently in the *New England Journal of Medicine*.^[1] The study relates to disseminated cancer with no known primary – originally a very bad prognostic scenario. The above study showed that targeting the particular chemical features of each cancer resulted in improved disease-free survival over maintenance of standard chemotherapy. One more example of how cancer treatment has changed over the last couple of decades – an amazing, if fairly slowly evolving, revolution.

Treatments may be expensive but, in a sense, this is a better problem than a counter-factual where these discoveries had not been made. Not only are these new treatments more effective, but they are less toxic thus improving quality of life and productivity. Indeed, improved productivity of cancer victims – anyway those who are working – may reduce the net costs of treatment to society. And I am not confining this point to paid labour.

Reference:

1. Park R & Saeed A. [Immunotherapy in Colorectal Cancer - Finding the Achilles' Heel](#). *NEJM Evid.* 2024; 3(6).



The Rise of Value-Based Contracts in Healthcare: Helping or Hindering Doctors?

Peter Chilton, Research Fellow

As approaches to healthcare continue to evolve, value-based contracting is an increasingly popular approach for improving quality of care. By linking doctor and hospital payments to specific quality metrics, it is hoped providers will be incentivised to deliver better outcomes for patients.

However, a Research Letter published in *JAMA Health Forum* suggests that the reality of value-based contracts may be more complex.^[1] Analysing data from primary care physicians (PCPs) employed by a US-based integrated health system between 2020-2022, showed that, on average, PCPs were being incentivised to meet 57 different quality measures at the same time. These measures related to everything from blood pressure control to cancer screenings, and were spread across multiple value-based contracts with different payers, such as commercial insurers, Medicaid, and Medicare.

The researchers note that this level of complexity is unlikely to lead to meaningful improvements, and may in fact have the opposite effect, essentially undermining the very goals of value-based care via an overwhelming administrative burden that distracts from the core work of caring for patients.

The researchers also found differences in the number and type of quality measures across payer contracts. Medicare contracts, for example, had significantly more quality measures on average than commercial or Medicaid contracts.

These findings suggest healthcare policymakers and system leaders need to take a hard look at how value-based contracts are being designed and implemented. While the intentions behind these models are good, the execution seems to be falling short in ways that are counterproductive.

In an era when physician burnout is a growing crisis, it's clear there is a need to simplify and streamline quality measurement, rather than continually adding more complexity. Value-based care holds great promise, but only if the right balance can be found, with structures in place to support those on the frontlines.

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1. Boone C, Zink A, Wright BJ, Robicsek A. [Value-Based Contracting in Clinical Care](#). *JAMA Health Forum*. 2024; 5(8): e242020.
2. Lilford R. [Burnout Among Doctors: Seed or Soil](#). *NIHR ARC West Midlands News Blog*. 2020; 2(1): 7-8.
3. Chilton P. [Interventions with Human-Centred Design to Improve Well-Being](#). *NIHR ARC West Midlands News Blog*. 2023; 5(4): 11.



Antibiotic Distribution Reduces Child Deaths in Africa

Peter Chilton, Research Fellow

A large clinical trial in Niger has found that giving the antibiotic azithromycin to young children twice a year can significantly reduce deaths.[1]

High child mortality remains a major problem in many parts of sub-Saharan Africa. In some areas, nearly 1 in 10 children do not reach their 5th birthday. While there has been some progress in recent years, new approaches are still needed to meet United Nations Sustainable Development Goals for reducing child deaths.

Previous research had shown that mass distribution of azithromycin to children could lower death rates, but it is not known how best to implement this. For example, should it be given to all young children or just infants? Would it still be effective alongside other health programmes?

To answer these questions, researchers writing in the *New England Journal of Medicine* assigned more than 380,000 children from over 3,000 rural communities in Niger to one of three groups:

1. All children aged under five years old to receive azithromycin twice a year
2. Only infants under one year old to receive azithromycin twice a year, with older children getting a placebo
3. All children to receive a placebo.

After two years of follow-up, researchers found that when azithromycin was given to all children under five, overall deaths were reduced by 14% compared to placebo ($p < 0.001$). However, when it was limited to just infants under one year, there was no significant reduction in deaths compared to control.

Further analyses showed that azithromycin was still effective even when the communities had lower mortality due to receiving other interventions, such as seasonal malaria prevention.

While promising, the researchers note that the development of antibiotic resistance needs to be closely monitored with widespread use of azithromycin. Balancing the immediate life-saving potential against longer-term resistance concerns remains an important consideration.

As the global health community continues to work towards the UN goals for child survival, this study marks a significant step forward in the fight for reducing child mortality in sub-Saharan Africa.

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1. O'Brien KS, Arzika AM, Amza A, et al. [Azithromycin to Reduce Mortality — An Adaptive Cluster-Randomized Trial](#). *NEJM*. 2024; **391**: 699-709.

The Role of Evaluation in Highlighting Impact: The Case of Managing Deterioration Within Care Homes

*Dr Sarah Damery, Research Fellow,
Long Term Conditions theme, University of Birmingham*

There is a growing recognition of the need to identify and manage deterioration in care homes to improve resident care. People living in care homes may be frail and have complex care needs, making them susceptible to sudden and unpredictable illness. Care home residents are disproportionately represented in transfers to A&E and hospital admissions, yet many emergency admissions from care homes could be avoided if the signs that a resident was becoming unwell were identified and managed early. Care home staff are ideally placed to recognise these often subtle 'soft' signs of deterioration, but varying skills and competencies within the care home workforce may hamper efforts to do so, worsened by a lack of appropriate pathways through which to escalate resident care when concerns arise.

The national [Managing Deterioration Safety Improvement Programme](#) (ManDetSIP) was introduced to identify best practice in patient safety, promoting continuous learning and quality improvement in care homes to reduce the risk of harm. ManDetSIP implementation was led locally by colleagues at Health Innovation West Midlands (HIWM). The goal was to support the adoption and spread of deterioration management tools within care homes, improve staff skills in recognising deterioration and collaborate with multiple system partners across health and social care to define pathways for managing deteriorating care home residents.

Researchers from the long term conditions theme of ARC West Midlands carried out a rapid, independent evaluation of ManDetSIP across the region, commissioned by HIWM. This involved analysing multiple information sources and interviewing key stakeholders to assess programme implementation and outcomes. The evaluation highlighted multiple impacts:

- Service delivery and capacity: 98% of West Midlands care homes participated in deterioration management training; 74% adopted deterioration management tools and 43% showed sustained adoption for at least 12 months.
- Economic impact: Data demonstrated a 1% reduction in 999 calls, 4% reduction in hospital admissions and 5% reduction in hospital stay. If scaled up across England, this would equate to 31,000 fewer 999 calls, 45,000 fewer emergency admissions and c. 500,000 fewer bed days.
- Systems impacts: The formation of multiple deterioration and care home patient safety networks and escalation pathways allowed a consistent approach across the region and shared learning between the six participating ICBs.
- Skills and workforce: A webinar series trained care home staff to use deterioration management tools, and embed their use into routine resident care.
- Operational impacts: Policy was adapted to embed deterioration management as an expected standard in Quality Assurance Frameworks for sustained, long-term adoption.

Through its independent assessment of ManDetSIP implementation, the ARCWM evaluation enabled HIWM to demonstrate the impacts of their programme, which has now been recognised by NHS England and adopted as a national example of good practice in achieving service change and cross-system collaboration. HIWM's approach went on to be highly commended in the 'Provider Collaboration of the Year' category at the 2023 Health Service Journal (HSJ) awards.

Latest News and Events

PhD Student View on NIHR Doctoral Training Camp

Clare Macdonald, a GP and PhD student within our [Maternity theme](#) (*researching the GP postnatal maternal 6-8 week consultation*), recently attended the 15th NIHR Doctoral Training Camp. Knowing how important putting together successful grant applications is for an academic career, Clare attended knowing this was a great opportunity and was delighted to be given a place.

The first day included a range of highly relevant and inspirational talks from excellent speakers about postdoctoral pathways and support available within NIHR as well as introducing the process of grant writing. In teams their main task was to prepare, in full, a grant application for the fictional 'Making People Healthier' research programme. This would include a detailed proposal, rationale, costings, research team details, timeline and plain English summary, delivered to a strict deadline around 24 hours

later. Claire's team quickly settled on a topic, and with expert mentoring from an experienced academic and PPIE expert the application was delivered just on time – they all agreed that they had never felt so invested in something that wasn't real!

On the final morning, all teams presented their project and took questions from the panel. The composition of the course and opportunity to connect with other PhD students from across the NIHR infrastructure were amazing. Clare's team's submission was the winning application. Clare would strongly encourage anyone given the opportunity to attend future iterations of the course. Clare also provided feedback that the composition of the course and opportunity to connect with other PhD students from across the NIHR infrastructure was amazing.



Latest National NIHR ARC Newsletter

The September issue of the NIHR ARCs Newsletter is now available at: <http://eepurl.com/iWYwXU>. This issue includes news of an inter-cultural toolkit for those working with asylum seekers; ADHD assessment technology; and research on improving communication with families when babies are harmed in maternity services.

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

ARC WM Seminar Series

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

- 2 October 2024, 12-1pm “*Mental Health: Challenges of conducting school-based mental health research and how to overcome them*” presented by Helena Tuomainen / Colin Palmer.
- 24 October 2024, 10-11am (*details forthcoming*)
- 3 December 2024, 12-1pm “*Admissions for Malnutrition and Vitamin Deficiencies in England 2001-2021*” presented by Katharine Reeves.

The NIHR have recently announced Impact Prizes to celebrate researchers and teams who have maximised the impact of their research and whose research has transformed people’s lives or promoted economic growth. This is open to those who have received NIHR funding or support across the range of areas NIHR funds.

Funding: NIHR Undergraduate Internship Programme

The NIHR Undergraduate Internship Programme aims to engage students from under-represented professions in the early stages of their academic studies to consider a career in health and social care research. Early to mid-career researchers can apply to host up to three interns who will undertake a fully-funded placement in the area they are interested in pursuing. The researcher will gain valuable supervisory and grant application experience.

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

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

NIHR Impact Prizes

For further information, please visit: nihr.ac.uk/about-us/our-impact/impact-prizes.htm. Applications can be made between **3 October and 13 November 2024**.

For further details, including the disciplines being prioritised, please visit: nihr.ac.uk/funding/nihr-undergraduate-internship-programme-round-2/36598. Closing date is **7 November 2024**.

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

Dewan M, Schachna E, Eastwood K, Perkins G, Bray J; International Liaison Committee on Resuscitation Basic Life Support Task Force. [The optimal surface for delivery of CPR: An updated systematic review and meta-analysis.](#) *Resusc Plus.* 2024; **19**: 100718.

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Gerritsen SE, Bolhuis K, van Bodegom LS, Maras A, Overbeek MM, van Amelsvoort TAMJ, Wolke D, de Girolamo G, Franić T, Madan J, McNicholas F, Paul M, Purper-Ouakil D, Santosh P, Schulze UME, Singh SP, Street C, Tremmery S, Tuomainen H, Dieleman GC, Mesman E. [The Association Between Trajectories of Self-reported Psychotic Experiences and Continuity of Mental Health Care in a Longitudinal Cohort of Adolescents and Young Adults.](#) *Schizophr Bull.* 2024: sbae136.

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