

BARRIERS TO MEANINGFUL ENGAGEMENT IN EVIDENCE SYNTHESSES

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WORK IN PROGRESS: Please don't cite without asking



**” MEANINGFUL
ENGAGEMENT ”
USUALLY MEANS**

The range of patients, carers and citizens is diverse (including seldom-heard groups)

They are supported as needed to contribute to the project *from start to finish*

They can talk freely (including ‘beyond the medical aspects’) and their voice is valued

They receive training, mentoring, practical support, reimbursement and feedback

Everyone’s role is clear and understood

ANOTHER FRAMING
OF “MEANINGFUL
ENGAGEMENT” IS
PHILOSOPHICAL



WHAT HAPPENS WHEN PATIENTS AND CITIZENS “ENGAGE” WITH EBM’S ACTIVITIES?

Research teams are nice to them (e.g. because journals ask about PPI)

They bring their lived experience and their values

But these aren't RCT-shaped. Hence, BY DEFINITION, patients' input is not “best evidence”

THE IMPORTANCE OF PRACTICAL RIGOR

- Conventional systematic review uses *procedural rigor*: rule-based, precise, auditable
- We propose *practical rigour*: **acknowledging, identifying and fully exploring the multiple kinds of knowledge which are needed to provide review results that can inform ethical, appropriate, effective action in a particular context**

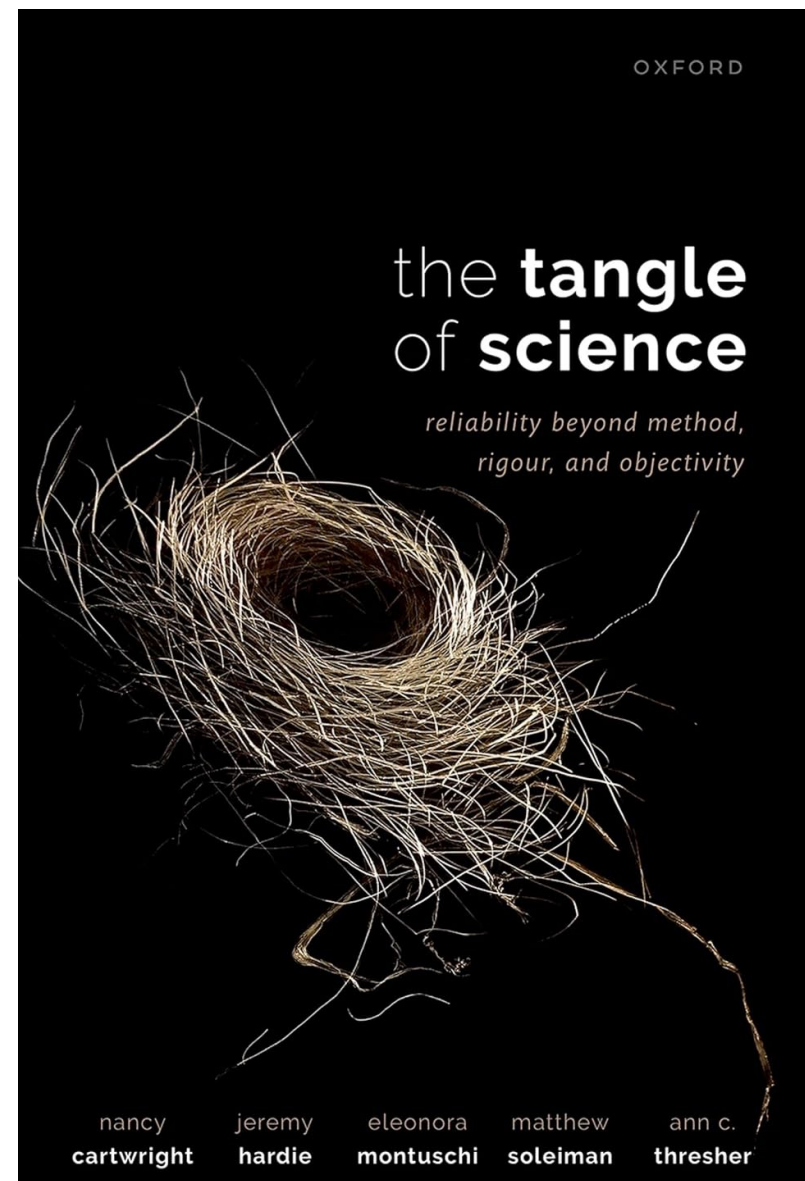


Includes experiential knowledge, 'local knowledge', evidence about values, and more



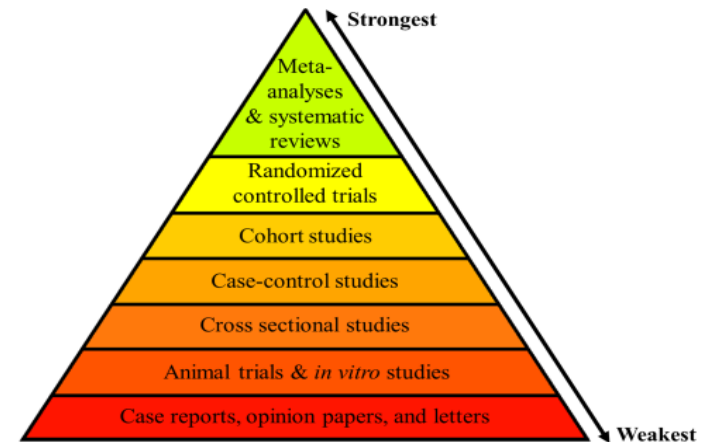
EVIDENTIAL RICHNESS: SCIENCE AS A 'TANGLE'

- Scientific findings are not atomistic; they are nested in a 'tangle' of other related findings
- All these findings must *cohere*
- Any individual finding must *make sense* in relation to the wider body of knowledge
- Associative findings (e.g. RCTs) are made more robust if they cohere with mechanistic (how/why) findings

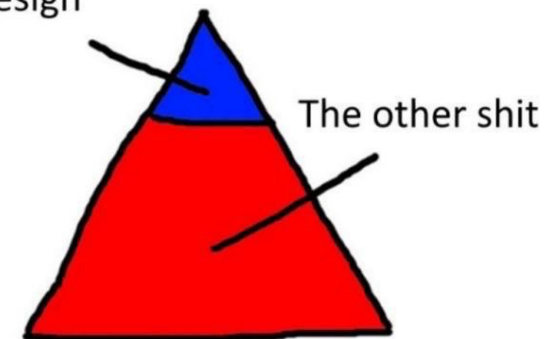


THE IMPORTANCE OF EVIDENTIAL RICHNESS

- Multiple kinds of evidence
- Depth and detail
- Quant and qual
- Contextual evidence: it worked *here* but it didn't work well *there* because...
- An over-arching narrative within which all the evidence comes together and *coheres*



Thoughtful, well-conducted studies of any design



THE IMPORTANCE OF VALUE- ORIENTATION

Conventional systematic review tries to keep values/perspectives out of the mix through concerns about “bias”. Hence, bringing in patient perspectives can prove tricky

We suggest that the best evidence syntheses will *embrace* people’s values and perspectives (we distinguish carefully between these and pernicious biases)




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CRITERIALISM VERSUS DELIBERATIVISM

CHERYL MISAK

“I was one of the group that produced “An Official .. Policy Statement: Responding to Requests for Futile and Potentially Inappropriate Treatments in Intensive Care Units” (Bosslet et al. 2015). [...]


I am a philosopher. ... I am also an ex-ICU patient, one who existed for weeks in full multiple organ failure and on the edge of futile or medically inappropriate treatment.”



**CRITERIALISM
VERSUS
DELIBERATIVISM**

- Criterialism: basing tricky clinical judgements on formal criteria (e.g. biomarkers, thresholds, scores etc)
- Deliberativism: a collaborative process in which clinicians, patients, and families openly *deliberate* about goals, probabilities, burdens, and competing values rather than relying on supposedly definitive rules

This has parallels to patient input in evidence syntheses



THE IMPORTANCE OF EXPERT DIVERSITY

- Conventional systematic review has a hierarchy of expertise, with statistical methods experts at the top (topic experts allowed if carefully controlled)
- We suggest this hierarchy should be replaced by *democratic deliberation between methods experts (including qualitative experts), topic experts and lived-experience experts*
- The philosophical underpinnings of this shift run to 20,000 words

PRESERVED: A PROPOSED NEW GOLD STANDARD FOR EVIDENCE SYNTHESIS



Practical Rigor in
Evidence Synthesis



Evidential Richness



Value-orientation



Expert Diversity

THANK YOU FOR YOUR ATTENTION

Paper 1 submitted to Research Synthesis Methods

Paper 2 in preparation for Medicine and Philosophy

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Nancy Cartwright (U of Durham)

