

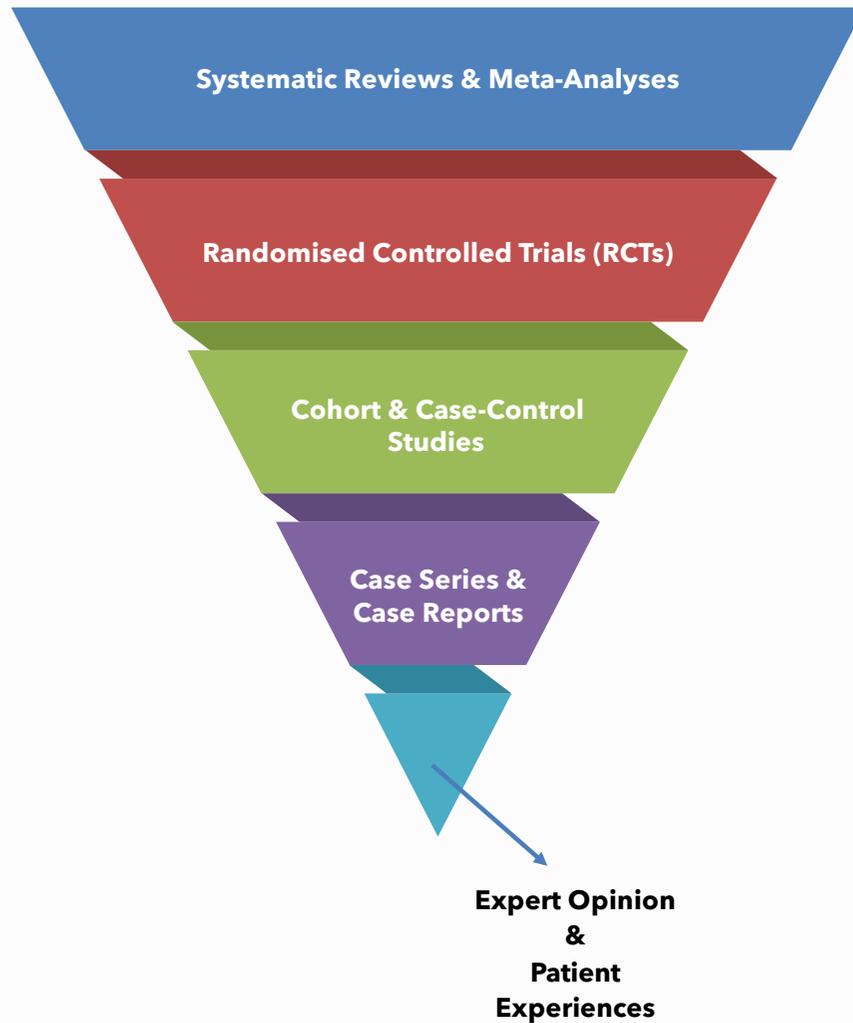


Beyond Patient Preference

**Challenging Epistemic Authority in
Evidence-Based Medicine**

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Evidence Based Medicine



Traditionally

EBM establishes a hierarchy of evidence where Systematic Reviews and Randomized Controlled Trials (RCTs) sit at the top.

"Unsystematic clinical experience" and expert opinion are demoted to the very bottom.

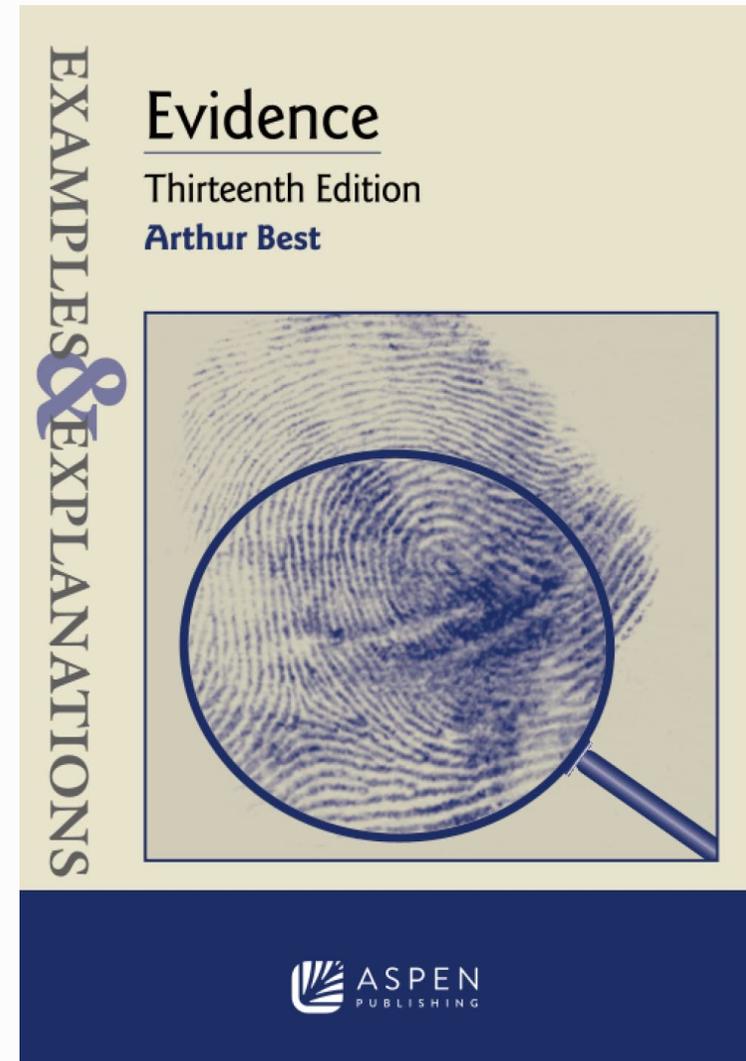
Why?

1. Avoid bias
2. Unsystematic observation cannot account for "regression to the mean," the placebo effect, or the natural history of disease
3. 1992 EBM Working Group: intuition and unsystematic experience are "insufficient grounds for clinical decision making" because they lack the structural capacity to distinguish evidence from noise.

Values Vs Evidence

: EBM proponents argue that while patient values are key in decision-making (axiology), they have zero weight in *evidence assessment* (epistemology).

Patients therefore can claim *normative* authority—the capacity to refuse treatments, for e.g.—but not *epistemic* authority—that is, the authority over what counts as evidence, nor when evidence suffices.





Knowledge- how vs knowledge- that

Knowledge-That (The Evidence):

- What do trials and data tell us?
- Relies on a strict hierarchy that values systematic reviews and RCTs above all else.

Knowledge-How (Clinical Expertise):

- How do we apply this top-tier evidence to a specific patient?
- Source: Clinician's tacit skill and judgment.

Values and EBM

- In the EBM framework, value-based claims (e.g., "I want to try this") are not knowledge claims at all.

Project:
**MRFF Stem Cell
Therapies Mission**
(Stream 4)
2007623



Aim: determine when and how stem-cell-based interventions (SCBIs) should move from clinical trial → clinical innovation → standard practice



Design: 47 stakeholder interviews (patients, carers) regarding living with cerebral palsy; osteoarthritis; multiple sclerosis



47 semi-structured interviews across Australia



Framework-led coding with room for concept formation

Knowledge-when

Epistemic claim re: sufficiency

We know enough right now to standardise this treatment

Distinct

Are presented as *knowledge claims*:

“we know enough now” – rather than as mere statements of preference (“we want it now”) or risk appetite (“we will try anything”)

Comparison to professionals

Professionals refer instead to RCTs, guidelines, duties, etc. Basis of judgement the weight of scientific evidence

Distinct basis

A mix: Identity/Justice and Nosomathia (lived illness knowledge) as well as hybrid lay translations of scientific literature.

Exemplar

- (i) **“In Australia... it’s only been done 10 years now... on the MS website they do post the reports of [X Hospital]... the percentage... in relapsing remitting – 87% which is high... The amount of deaths... under 1%... In places like Russia and in Mexico they’ve been doing it for 30 years... the success rate was really good. So you can only go on what’s being posted. I tried to read some of the scientific stuff but it was a bit over my head...”** *Appeals to sources (national reports + international longevity) functioning as evidence.*
- (i) **“Well at the moment [X Hospital] would say when you’re in relapsing remitting there’s a 87% chance of success. That’s pretty high...” ... “Oh no, on the contrary [you should do it then]... I say that’s the most promising time to do it... had I had the choice, if I could have had stem cell transplant immediately after my first relapse... maybe I wouldn’t have had the time where I couldn’t walk 200 m.”** *Link a numerical success rate to a timing threshold and argue practice should track that.*

Knowledge-when and challenges

Not a claim to the *same* type of knowledge

Consumers rarely claimed that they knew more about the *science* than medical professionals.

AUTHORITY appealed to is instead **nosomathia**: *knowledge via illness*.

Sustained, embodied experience of disease plus observation of one's own and peers' responses is claimed to justify conclusions about whether a therapy is ready for broader uptake.

Because knowledge-when is an epistemic claim it cannot be easily dismissed as a mere preference, nor a misunderstanding of the evidence.

It's a claim about *the source of evidence* and *the sufficiency of same*.

What we're **NOT** claiming

Does not have an automatic claim to override medically grounded knowledge—that. Other reasons could suffice (e.g. justice, the duties of professionals, etc)

Nor does knowledge—when necessarily confer *normative* authority.

Our point is **epistemic**: these claims are about when evidence is sufficient to justify an action. As a result, conflating these claims with expressions or preference, risk toleration, or epistemically empty claims misrepresents their character.

Thank you

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