

Health Literacy in Clinical Trials

A Patient Perspective



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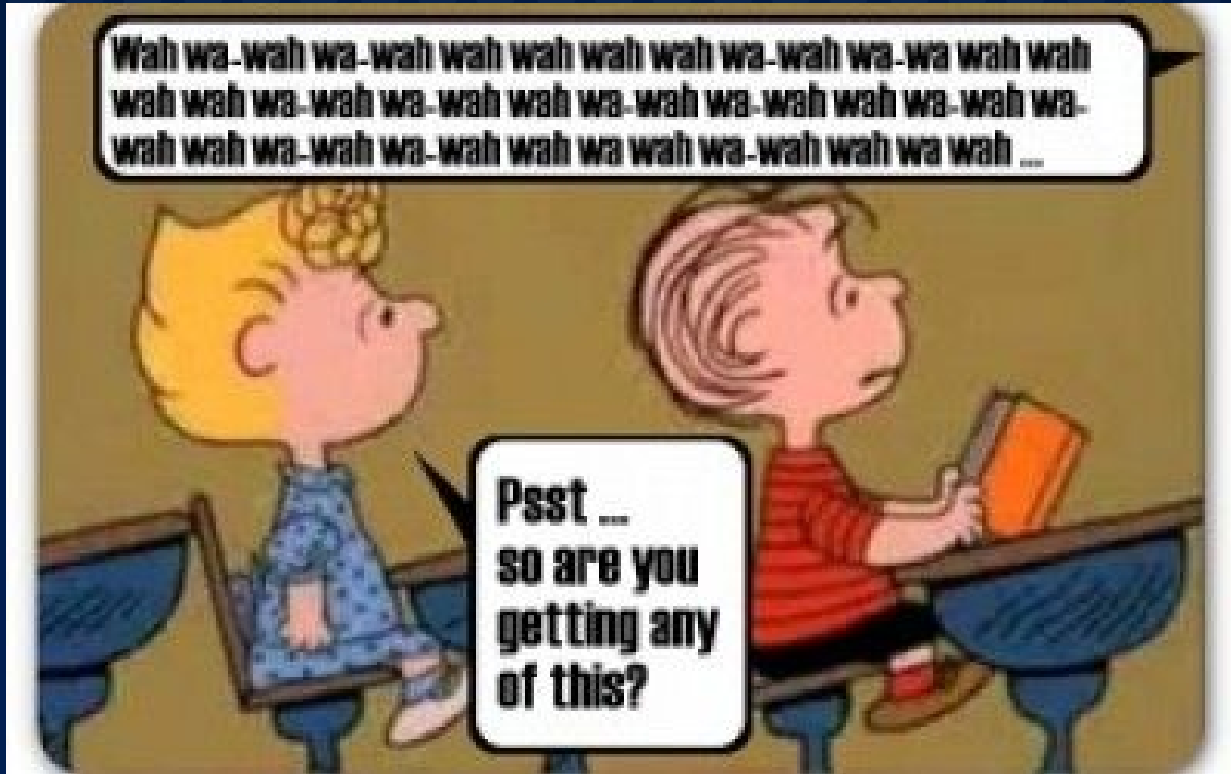
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Patients **are the most *underutilized* resource in healthcare.**

What can we learn from the Patient Journey?

The Charlie Brown Theory of Clinical Trial Education Comprehension





Patient Perspective on Health Literacy...



... it's about context, situation, technology, comprehension



Everyone's talking about Informed Consent...

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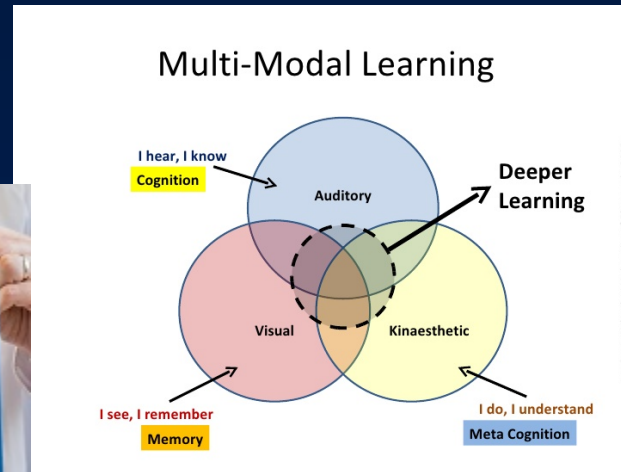
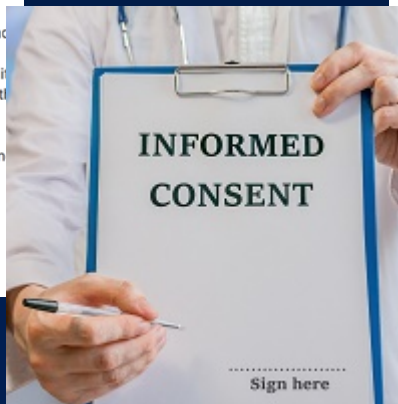
TOOLS SHARE

Informed Choice: A Needed Paradigm Shift

As the lead for health literacy at the Agency for Healthcare Research and Quality (AHRQ) and co-chair of the Health and Human Services Health Literacy Workgroup, I champion clear communication and patient engagement. I'm an adherent of the slogan popularized by quality improver Don Berwick, "Nothing about me without me." I believe that if we are to overcome the inherent power differential between clinicians and patients, we need a paradigm shift. The current state of affairs, whereby people commonly consent to treatments their clinicians recommend without full information, needs to be transformed into a proactive one of informed choice.

Informed choice requires:

- Easy-to-understand information about the benefits, risk, and harms of all options;
- Eliciting patients' and families' goals and values; and
- Impartial help with making the decision.



... let's start talking about **EDUCATED CONSENT**



Educated Consent is...

- Presentation of information in ***a mode*** the patient needs
- Presentation of information on ***a timeline*** the patient needs
- Presentation of information ***to the patient's healthcare team*** (Caregivers, family members)

... the right information at the right time in the right context

Best Practices for Health Literacy



Design

Develop and design information products and solutions with the patient perspective at the forefront.



Engage

Build consistent points of interaction for patients to learn in ways that they want. What works best? Paper, web based presentations, video, audio.



Activate

Consider the environment for information sharing. Can the patient act on the information presented.



Thank you