Low health literacy is a big problem

93 million Americans lack health literacy skills to understand and use health information.

1 in 5 adults have “below basic” HL skills.

BTW, this includes people with CREDENTIALS behind their names too!

NAAL, 2003
Patient issues start with…

Confusing terms & discussions
(mis) Diagnosis
Costs (all kinds)
Focus: ‘data,’ not patients
Clinical trials?
   Where, eligibility, procedures, informed consent, costs, side effects, communication, delays, fear, results
What’s next?
What do patients want to know?

✓ I am not alone (others before me)

✓ Why are you doing it?
  • What is known/unknown

✓ What to expect
  • Exploratory v. validated

✓ How bad can it get… ‘safe’ word?

✓ What happens after?

MORE THAN INFORMED CONSENT © Patient Advocates In Research (PAIR)
e.g. Cancer & Leukemia Group B

CARE Committee 1998-2010
Co-Chair: Deborah Collyar

Themes: Service, educational, and research activities

- Development
  - Reviews: Operational Concept Protocol
- Approval
  - Informed consent: Templates Lexicons
- Activation
  - Recruitment plan: Tools Special populations
- Recruitment
  - Tracking and advice: Resource networks Protocol evaluation Accrual Plan adjustments
- Endurance
  - “Retention” “Adherence” “Compliance”
- Results
  - Participant communication: Thank you letters Research summaries

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People (& providers) need the 4 Cs…

Clear Communication of Content in CONTEXT

For THEM, no matter their role in health
Please help us build this!

**NCPF & Roundtable on HL**
Develop a series of *HL decision-making templates* for practices to use with patients

**NCTN**
Test this series in different settings
- By stage, cancer type, population, culture?

**Publish results**
- JCO/JOP, etc. then AACI/AACR/ACS
- COC/ASCO/ASTRO
- ASCO/NCCN joint guidelines

**Endorsement**
- Payers
- Regulators

**Credentials**
Institutions, accrediting agencies endorse/use
- AAMC, CMEs, tenure track, etc.

Collyar (insomnia-induced moment!)
Which statement is correct?

A. “the patient failed the treatment”

B. “the treatment failed the patient”

Please stop this! Help us change the mindset.
Thank you! Get in touch

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What do patients want from immunotherapy?

Less hype, more realism
- Compare regimens > guidelines
- Integration w/other treatments
- Better care
- “C” word issue (cure)

Fewer irAEs
- > grade 2 can be serious
- Autoimmune is serious
- Possible age factors?

Report additional info
- Response rates
  - Comparable to chemotherapy
- Duration of response
- Financial toxicities
- QOL & PROs

https://jitc.biomedcentral.com/articles/10.1186/s40425-017-0300-z
e.g. Crossover (treatment switching) 2016

Best Practices for the Design, Implementation, Analysis, and Reporting of Oncology Trials with High Rates of Treatment Switching

**International consortium**
Australia (IRB), UK (NICE), US (FDA)

**Multi-stakeholders**
Clinicians, regulators, companies, patient advocates, payers