Care & Clinical Trials for & *with* People & Patients

Health Literacy and Communication Strategies in Oncology

NCPF

July 15, 2019

Deborah Collyar

PAIR: Patient Advocates In Research

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

AXIOS NEWSLETTERS SECTIONS SPECIAL FEATURES MORE

Caitlin Owens Jul 9, 2019

Doctors don't make better patients

Doctors — theoretically, the best-informed patients out there — don't receive significantly more high-value care than non-doctors, according to a new National Bureau of Economic Research paper.

Why it matters: Many policies are designed based on the idea that if people have more information, they'll be better health care consumers.

- For example, this is the theory behind high-deductible insurance. One possible explanation for why it hasn't been very effective in improving patient health is because consumers aren't knowledgeable enough to steer themselves toward high-value care.

The bottom line: "These results provide a rough boundary on the extent to which additional information disclosure (beyond prevailing levels) can be expected to improve the delivery of health care in the U.S.," the authors write.

Go deeper: Higher deductibles aren't getting people to price shop

Patient issues start with…

Confusing terms & discussions

(mis) Diagnosis

Costs (all kinds)

Focus: ‘data,’ not patients

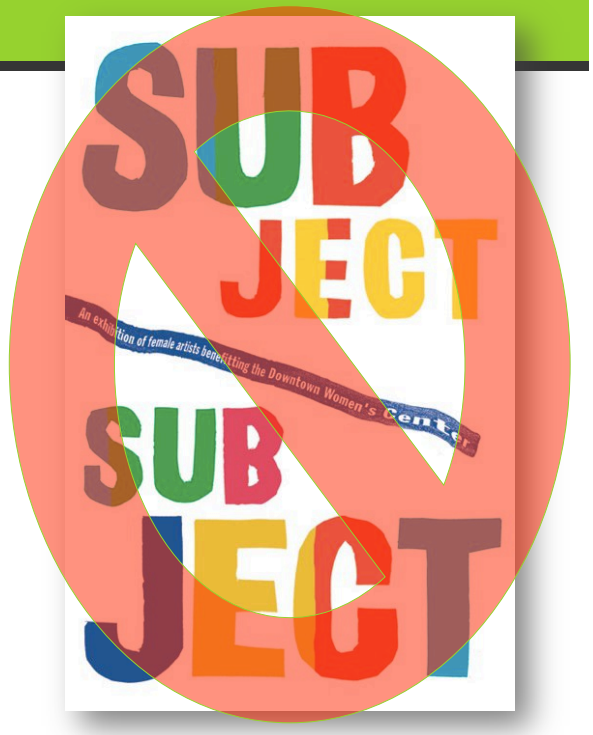
Clinical trials?

- Where, eligibility, procedures, informed consent, costs, side effects, communication, delays, fear, results

What’s next?

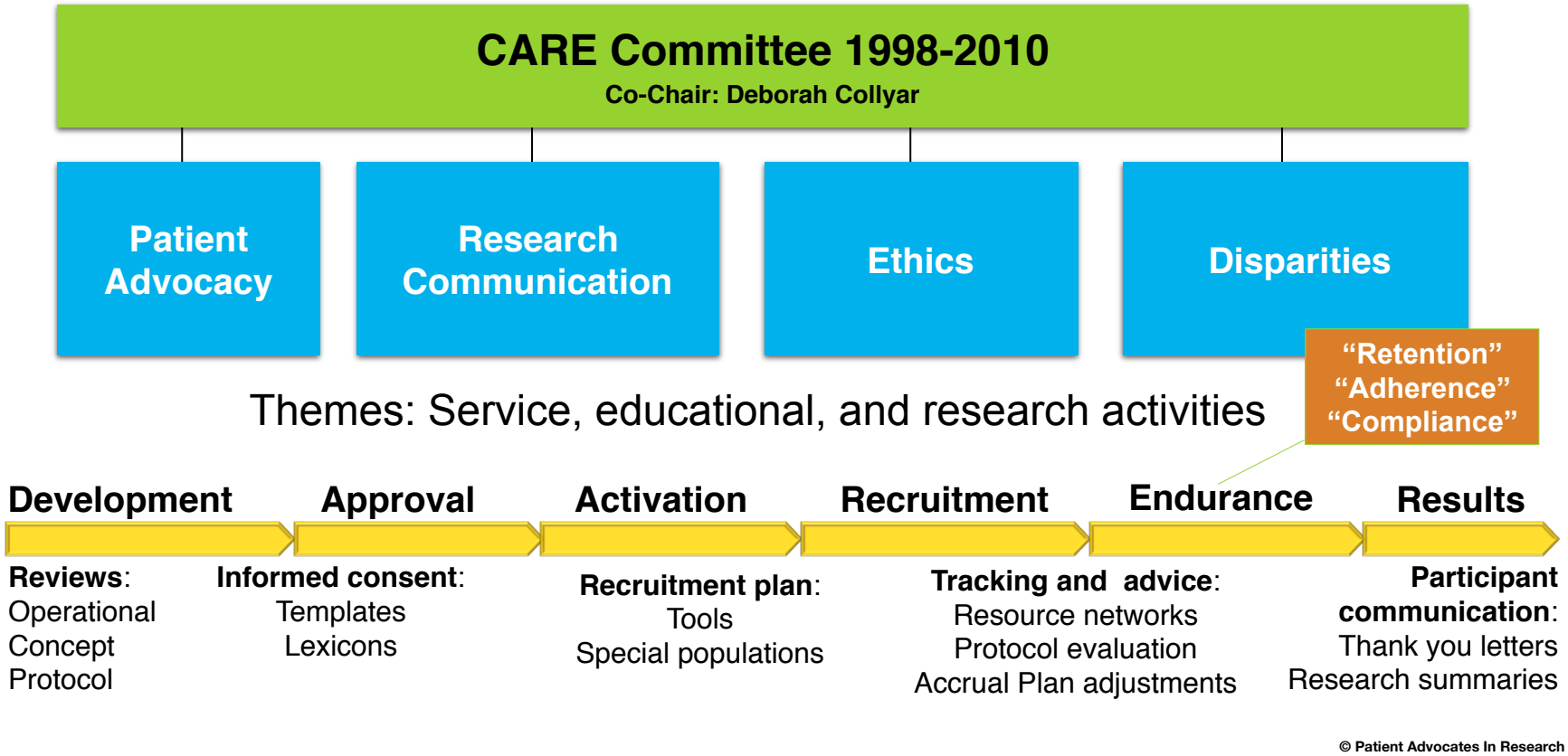
What do patients want to know?

- ✓ 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

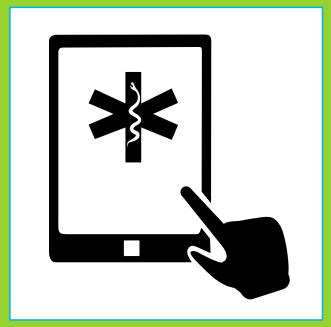
e.g. Cancer & Leukemia Group B



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.

With PATIENTS, of course!

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

Patient Advocates In Research (PAIR)

Where research meets reality

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)

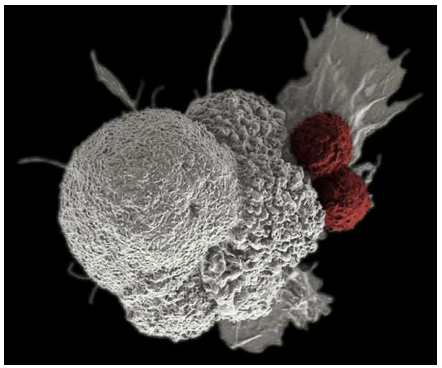
Fewer irAEs

- ≥ grade 2 can be serious
- Autoimmune is serious
- Possible age factors?

CONTEXT

Report additional info

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



https://www.inspire.com/groups/american-lung-association-lung-cancer-survivors/discussion/opdivo-beware-the-hype-and-commercials/

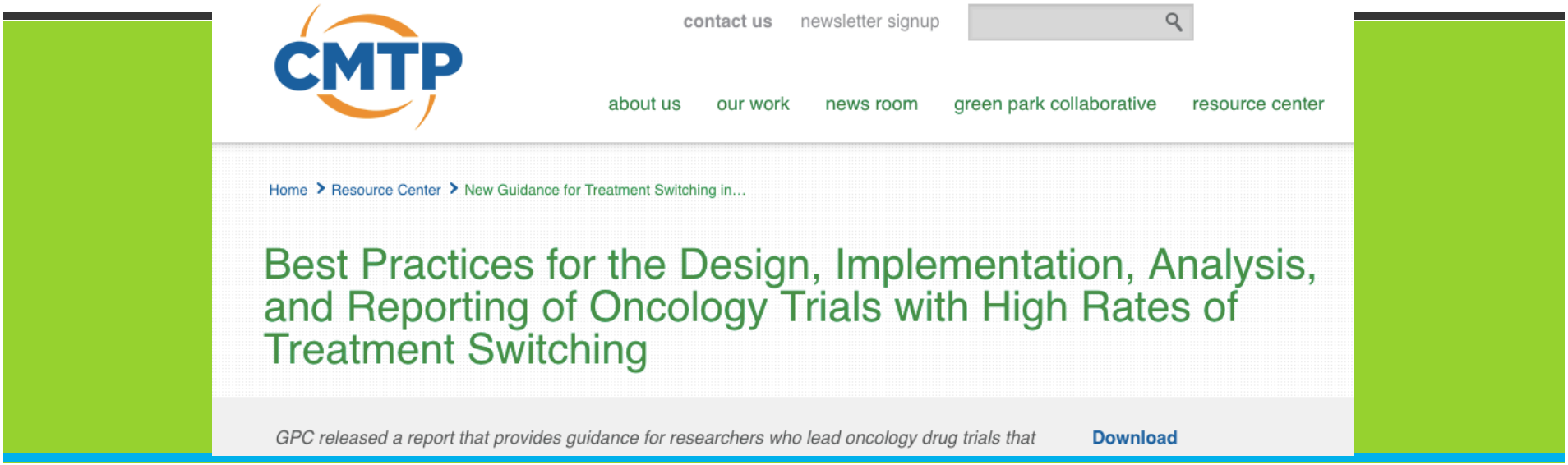
https://jitc.biomedcentral.com/articles/10.1186/s40425-017-0300-z

http://yourcenter.uvacancercenter.com/autoimmune-disorders-and-cancer-whats-the-connection/

https://www.medscape.com/viewarticle/897946

http://bit.ly/2LD4YPX

e.g. Crossover (treatment switching) 2016



International consortium

Australia (IRB), UK (NICE),
US (FDA)

Multi-stakeholders

Clinicians, regulators, companies,
patient advocates, payers