Worlds of “patient advocacy”
Our role?

• We partner with scientists everywhere
  • E.g. programs, policies, projects, protections, patients
  • Focus: results for PEOPLE

IF IT DOESN'T CHALLENGE YOU
IT DOESN'T CHANGE YOU
- FRED DEVITO
Citizen Science?

- Citizen scientists?
- Citizens ≠ Patients
- Citizens ≠ Advocates
- But they ARE the same PEOPLE
Issues from “citizen” side

- Stop siloing!
- World is accelerating
- Ethics can slow things, but important
- Relevance/becoming irrelevant
- Approach research/ethics in new ways
- We want to be useful, not used
Words matter

• For *whom* do we do clinical trials?

• Informed consent: not working!
Focus on the FUTURE

Patients want speed & will take risks
It’s a brave new world!