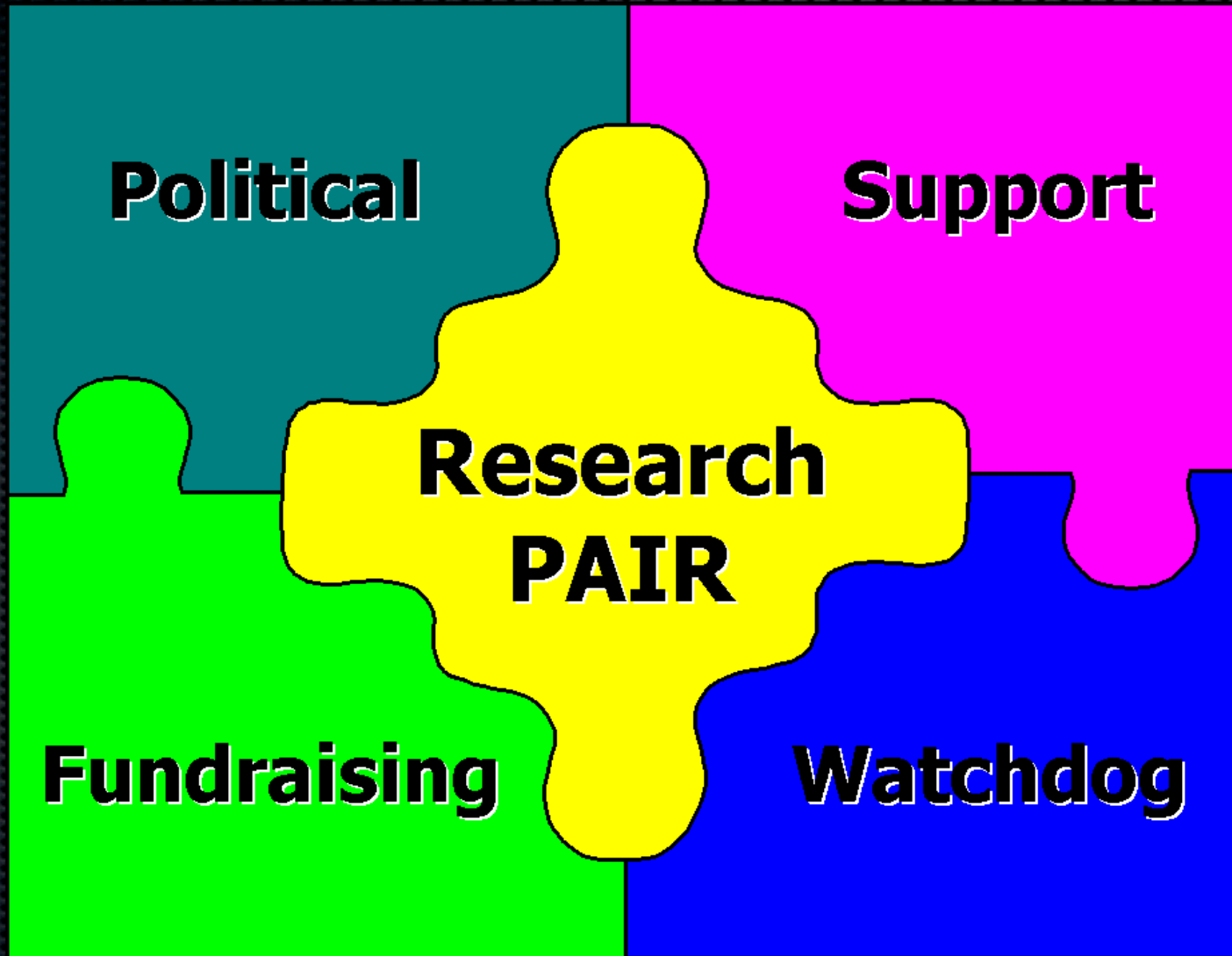


Worlds of “patient advocacy”



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?

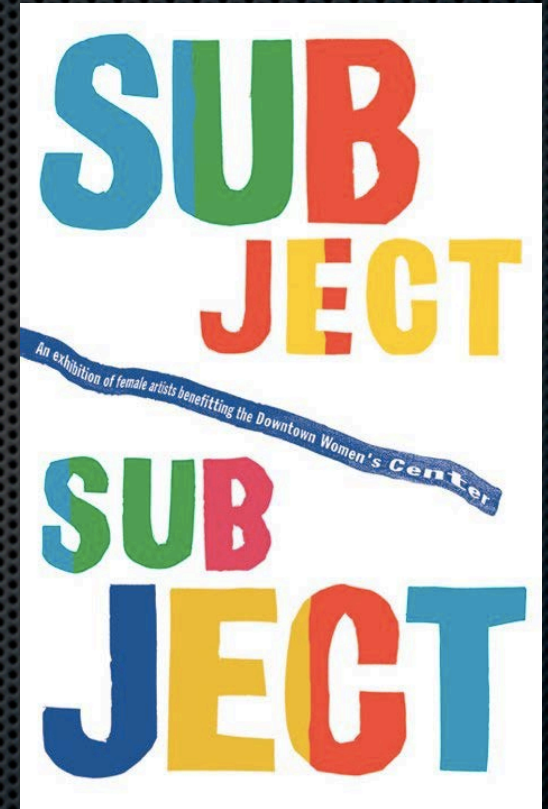
- Citizen scientists?
- Citizens \neq Patients
- Citizens \neq Advocates
- But they ARE the same PEOPLE

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

An advertisement for HSBC featuring a central image of a fingerprint with a QR code overlaid on it. The text "Be part of the future." is on the left, and "Your DNA will be your data." is on the right. The HSBC logo is at the bottom left.

Be part of
the future.

Your DNA will
be your data.

HSBC 

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