

Session II: Challenges and Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research

Pacing for Partnership

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Overall Challenges



Time



Trustworthiness



Transparency



Team Science Approaches



Frequent Approach: “Linear” Timelines

Ex. 1



Ex. 2





Continual, Iterative Engagement

Better study design from start to finish

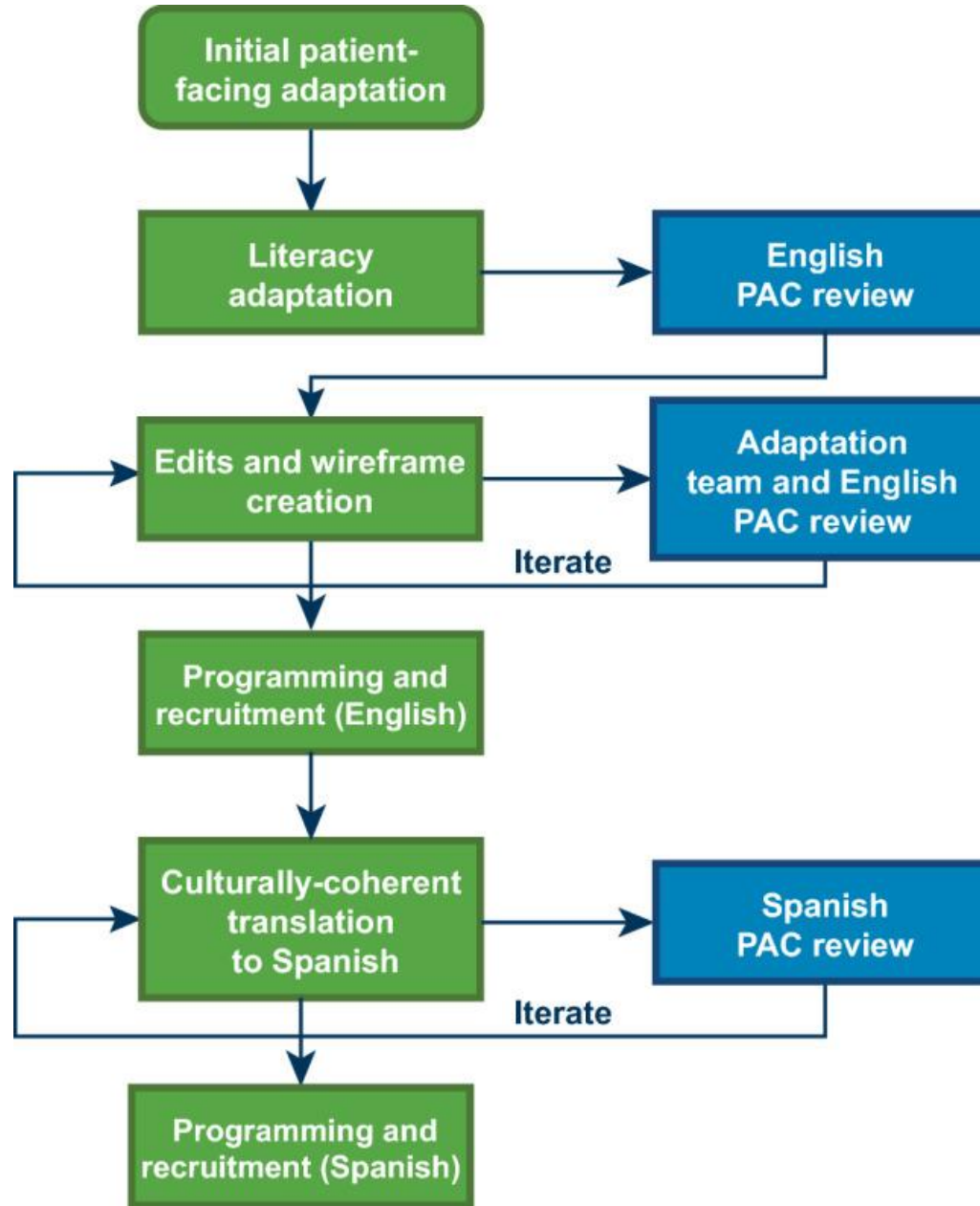
Community feedback on more than just one aspect of the study

Community participation in analytic thinking

More genuine community involvement and sustained relationships



Example: CHARM Study Challenges



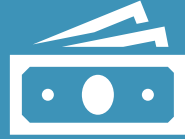
Mittendorf et al., *Fam Cancer*. 2022 Apr;21(2):167-180.

Mittendorf et al., *Hered Cancer Clin Pract*. 2022 Jun 10;20(1):22.



Time:

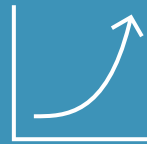
Challenges &
Opportunities



Budget



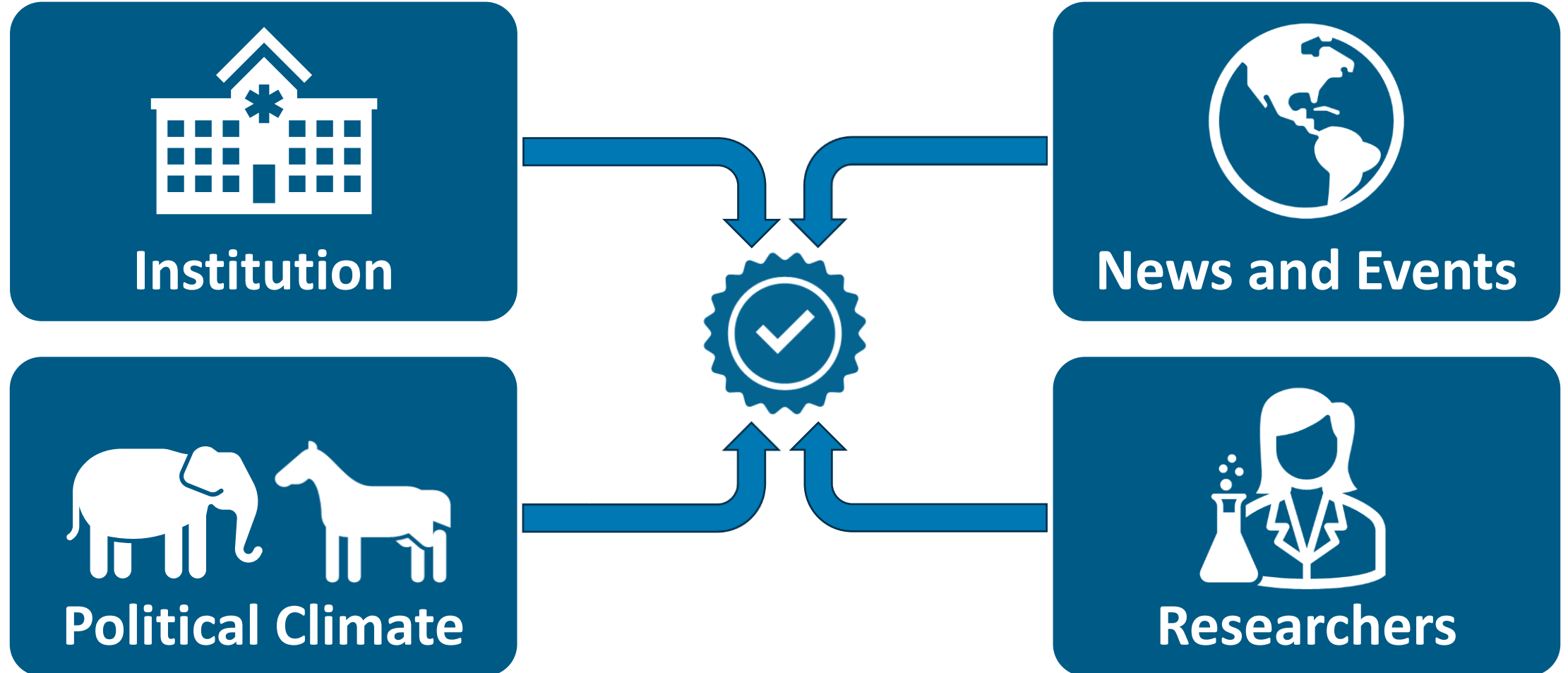
Grant Timelines



Sample Sizes



Trustworthiness is multifaceted





Interviews with transgender and gender-diverse genomics study participants

"I don't know that [TGD people] would necessarily – especially with our political climate – trust institutions or researchers just in general because they're like, 'Ohh no, no, I live in the South. I live in the Bible belt. If you ask me this, I'm gonna get put on a list'"

– Participant 4

“There has been the controversy recently of a bunch of medical records being released ...with people who received gender affirming care [at VUMC]...There's always a little fear in the back of my mind about loss of privacy.” –

Participant 3



Trust:

Challenges & Opportunities

Researcher Awareness

Researcher Engagement

Researcher Communication

Research Team Composition



Transparency: Concerns

“I feel like the research itself might be good, but I'm kind of concerned that you can't really control what happens when it goes out into the world... Realistically, it would probably get used... in a eugenics way.” – *Participant 2*

“It depends on, when I’m doing informed consent, what are you looking for and how is this going to be used?” – *Participant 4*



Transparency: Challenges & Opportunities

Literacy Adaptation

Avoiding Bait & Switch

Addressing Concerns Openly

IRB Reform



Team Science Approaches

Team composition

Power balance: hierarchies

Decision-making process



Team Science: Challenges & Opportunities

Avoid paternalizing

Counter hierarchies

Center voices

Take a seat

Funding & acknowledgements

- PREMM team (R01CA132829)
- CHARM study team & diversity supplement mentors (3U01HG007292-07S1)
- VGER study team (VUMC site of eMERGE IV) and VGER TGSD supplement team (3U01HG011181-04S1)
- FOREST study team and FOREST TGSD supplement team (3U01CA232829-01A1S1)
- Makenna Martin, MSGC

