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Bringing the IRB to the People and the People to the IRB

Let Meaningful Relationships Guide

01	02	03	04	05
Build the relationship and dedicate time to it	Receive and act upon feedback	Incorporate community voices in the regular conversation	Form a bridge with other community engagement groups at the institution	Form a bridge for investigators at the institution

Ideas & Real-World Examples

1. Policy advising; example, Spanish inclusion policy @ Utah

2. Community relationships resource list for investigators

3. Community IRB panels; example, Panel C @ Utah

4. Community engagement as continuing education for researchers and IRB members

5. Community expert ad hoc reviewer list

6. Community IRB and Academic IRB shared membership

7. New IRB application questions and expectations

Ideas & Real-World Examples

8. Research and ethics literacy exhibits, booths, social media, art, book clubs, science education; examples, @myIRBinUtah, science fair partnership, STEM Ambassador Program, library installation

9. Community leader and research community forums; example, UCRE conference

10. A Return of Results public, lay-friendly database
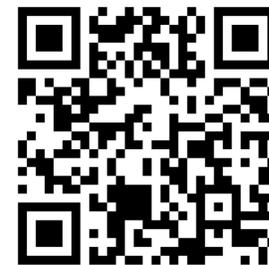
Community Committees

Community IRB members, Community Advisory Committees, Community IRBs, etc.

How can HRPPs better help these committees and members derive meaning from their work?

Can the Community IRB and Academic IRB overlap?

Does community engagement always have to come *before* IRB approval?

Can an IRB application be better tailored to ask for more community-centered information?

Why was Panel C created?

How can the IRB gain and integrate knowledge of communities into the review of research?

What happens if an IRB's membership is mostly non-scientists instead of scientists?

What happens if an IRB's community representatives are informed representatives of or voices from their communities?

Our concept of Panel C goes beyond the traditional concepts of community IRB member service and a community advisory board.

It gives a convened IRB's voting majority to non-scientist, community members, allowing their perspectives to be more readily considered and moves their perspectives beyond a mere advisory role.

What is Panel C & what does it do?

A fully constituted IRB panel with a non-scientist and community member majority.

RESPONSIBILITIES

Advance the University's IRB, Human Research Protection Program, and research community policies and practices to ensure respect for diverse Utah communities and research participants.

Evaluate research projects and make determinations for studies with unique community-based concerns.

Review participant study materials, such as consent forms and recruitment materials, to recommend improvements to literacy.

Panel C work to date: Jan 2022 - present

Has performed usual reviews for the IRB.

Has advised the University on a Spanish inclusion policy and its implementation for research.

Health literacy training in 2024.

Has advised on study-specific risk language for consent forms for studies with a controversial risk-benefit assessment.

Has participated in a focus group on how to use archived blood spots from autopsies in future research.

How did we make Panel C happen?

1. **Get to know community leaders.**

2. **Get funding and FTE support.**
   a) Pilot funds from VPR; promise of continued funding with successful results.
   b) Stipends for new IRB members
   c) Started with 0.5 FTE for IRB staff to organize the effort

3. **Identify an IRB Chair with a good fit.**

4. **Carefully invite membership.**
   a) We didn't want people to think our relationship with them was contingent on their joining the IRB.

5. **Train and establish the Panel C vibes.**
   a) It takes a lot of patience with training.
   b) Trust building and relationship building is important.

6. **Be more intentional with IRB operations.**

How have we benefitted from Panel C?

So far...

Great friendships and community relationships.

Learning about the Utah communities' successes, celebrations, concerns, struggles, and needs.

Excitement.

Passion.

Better IRB reviews.

Better research.

A new, more inclusive policy and practice for participants.

An option for researchers to get advice.