Panel 2: Making complex topics accessible

HPTN 052
STREAM Stage 1
NC-005

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Challenges

- GPPs encourage engagement with all key stakeholders
- Levels of research literacy varies amongst stakeholders
- Research results are complex, particularly statistical concepts, and difficult to make accessible to all audiences
- Adaptation of key data and messages for various audiences and methods of communication while maintaining integrity of scientific information is challenging

Source: Good Participatory Practice Guidelines for TB Drug Trials, 2012
Examples from STREAM Stage 1

• “Non-inferiority” trial

• Key conclusion from preliminary results => the intervention regimen didn’t meet pre-set non-inferiority criteria

• How best to explain concepts of non-inferiority and an intervention that is not non-inferior?
Examples from HPTN 052

- Interim results showed a relative reduction of 96% in the number of linked HIV-1 transmissions resulting from intervention
- Trial stopped early
- For an intervention that is so obviously effective, why did we have to do a trial at all?
Examples from NC-005

- Interim results were positive and statistically significant
- Implications of the results impacted another ongoing trial
- Disseminated widely to global, national and local stakeholders through conference presentation (CROI 2017), media (*Science*), webinars, communications workshops (CE Forum)
Concrete tips

Ongoing engagement and consultation is critical:

• *Developing understanding*: research literacy throughout the trial
• *Adaptive messaging*: preparing the facts for all audiences
• *Planning together*: dissemination planning with site-level partners
• *Collecting FAQs*: facilitating an ongoing dialogue with site-level CE partners to understand stakeholder questions and concerns throughout dissemination process
Discussion

• How can we ensure results are shared with a consistent message?
• What do participants really want to know about results? How much is too much? How much is too little?
• What techniques have panelists used to make statistical concepts understandable to participants and family members?
• What is the best strategy for preparing research partners to share results?