Good Participatory Practice

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Community/Public Engagement at KWTRP 2003 - 2020

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Technical Working Group on Good participatory Practice for STV – 2020 - present

• To support STV trial sites in planning, implementing and documenting Good Participatory Practice

• To develop tools to support GPP
  • GPP Handbook
  • GPP online training for practitioners
  • Tools and templates
    • Planning template, stakeholder mapping template
    • FAQs, Flipbook, leaflets, animations, planning forms, rumour tracking, CAB ToRs
Good participatory practice guidelines for trials of emerging (and re-emerging) pathogens that are likely to cause severe outbreaks in the near future and for which few or no medical countermeasures exist (GPP-EP)

Outcome document of the consultative process

Prepared by Dr. Catherine Hankins for the World Health Organization
December 2016

- https://www.who.int/publications/m/item/r-d-good-participatory-practice-for-covid-19-clinical-trials---a-toolbox
Who are the stakeholders?

- **National Stakeholders**
  - Ministries of Health, media, regulatory bodies

- **Broader Stakeholders**
  - Health NGOs, local policy makers, local media

- **Community stakeholders**
  - Local leaders, Community Advisory Boards, Local NGOs and CBOs
Why engage?

• To show respect and to ensure social value
  • To understand the local context in which the trial will take place
  • To convey risks and benefits of the proposed research and to listen and respond to community views, questions and concerns
  • To incorporate local views into the trial, its design and implementation, to determine feasibility and acceptability
  • To gain support for the trial and build “well-founded” trust
• GPP – engagement before, during and after the trial
Engagement before the trial

• Setting up a communications and engagement coordinating group
• Link between trial team, community, other stakeholders
• Planning engagement strategy
• Initial formative engagement/research
  • Stakeholder mapping
  • FGDs with different groups – exploring feasibility, acceptability, local input into implementation, advise on messaging to reduce stigma
  • Formation of a local CAB
Engagement **during** the Trial

**Deep/Narrow Engagement** - **Wide Engagement**

- Forming longer-term relationships
- Modest outreach?
- More participatory?
- More opportunities for mutual-learning?
- Limited representativeness?

- Shorter encounters?
- Greater outreach?
- Less participatory?
- Raising public awareness?
- Greater representativeness?

Davies et al 2019
Engagement during the Trial

Deep/Narrow Engagement.......................... Wide Engagement
Forming longer-term relationships...........
Shorter encounters?
Modest outreach?..................................
Greater outreach?
More participatory?..............................
Less participatory?
More opportunities for mutual-learning?....
Raising public awareness?
Limited representativeness?..................
Greater representativeness?

- Community meetings
- Lab open days
- Radio jingles
- Posters
- Media releases

Davies et al 2019
Engagement during the Trial

Deep/Narrow Engagement.................. Wide Engagement
Forming longer-term relationship versus shorter encounters?
Modest outreach? .......................................................Greater outreach?
More participatory? ..................................................Less participatory?
More opportunities for mutual-learning? .........................Raising public awareness?
Limited representativeness? ........................................Greater representativeness?

• CABs
  • Young Persons Advisory Boards
  • County health Management Team

• Community meetings
  • Lab open days
  • Radio jingles
  • Posters
  • Media releases

Davies et al 2019
Continued Engagement

Regular meetings with:
- Participants
- Stakeholders
- Community leaders
- Community Advisory Board

Share:
- Feedback, community views, rumours etc.
- Minutes and reports
- Recommendations on engagement and implementation - response

Regular meetings with internal engagement and communication team:

Global Solidarity Trial Engagement team
Engagement after the Trial Closes

• Maintaining transparency and open communication after trial closure:
  • Acknowledges the dignity of participant communities and their ethical right to participation;
  • Protects and preserves relationships built in the community;
  • Supports mutual respect and trust
  • Can improve uptake in policy and practice once a study is completed.

• Early planning
  • Consultation with the CAB – best ways of dissemination
  • Dissemination of results using a range of channels
  • Responding to questions and concerns
Tools which might be drawn upon/modified

• **Good Participatory Practice (GPP) with trial populations for the Solidarity Trial Vaccines (STV) Handbook**
  - [https://www.who.int/publications/m/item/good-participatory-practice-(gpp)-with-trial-populations-for-the-solidarity-trial-vaccines-(stv)](https://www.who.int/publications/m/item/good-participatory-practice-(gpp)-with-trial-populations-for-the-solidarity-trial-vaccines-(stv))

• **Working with Community Advisory Boards for COVID-19 related clinical studies**
  - [https://www.who.int/publications/m/item/working-with-community-advisory-boards-for-covid-19-related-clinical-studies](https://www.who.int/publications/m/item/working-with-community-advisory-boards-for-covid-19-related-clinical-studies)

• **Good Participatory Practice (GPP) for COVID-19 clinical trials: A toolbox**
  - [https://www.who.int/publications/m/item/r-d-good-participatory-practice-for-covid-19-clinical-trials---a-toolbox](https://www.who.int/publications/m/item/r-d-good-participatory-practice-for-covid-19-clinical-trials---a-toolbox)

• **Solidarity Trial Vaccines (STV) flipbook**
  - [https://www.who.int/publications/m/item/solidarity-trial-vaccines-(stv)-flipbook](https://www.who.int/publications/m/item/solidarity-trial-vaccines-(stv)-flipbook)

• **Online training**
  - [https://extranet.who.int/hslp/training/login/index.php](https://extranet.who.int/hslp/training/login/index.php)
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