Experiences & Challenges of IDIs & FGDs for Pandemic Ethics Research

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Pandemic Ethics Project Nepal

- Two sites
- NHRC- Central regulatory body- focus on WP1
- IOM, under Tribhuvan University- focus on WP2
- Objectives
  - WP1- conduct a scoping review of the related documents and publication
  - WP2 -conduct qualitative research – IDIs and FGDs to get an in-depth understanding of relevant stakeholders' perspectives

FGDs

- 10 groups
- Each with 8-12 participants
- COVID-19 patients- 4
- Trial vaccine recipients-3
- Emergency used authorized vaccine/drugs recipients-4
- Gender stratified

FGDs...

- Time: 120 min
- 2 research associates involved
  - One interviewer and one note keeper
- Conducted only after taking prior approval
- Conducted at the place of convenience to the participants
- Open ended questions

FDG..

- Audio recording
- Transcribed within 24 hours

IDIs

- 35
- Trial sponsors -5
- Research ethics committee members -10
- Researchers 10
- Regulators 5
- Humanitarian organization representatives 5

IDIs...

- At their convenient time and place
- 60-90 min
- Semi-structured
- At the end, asked to respond to the questionnaire
- Audio recorded

Current Status

- Completed all FDGs and IDs
- Preliminary analysis

Common Responses by Nearly all Participants

- Positive impression
- Detailed explanation of PTA and benefits sharing help raise their awareness
- Such studies being done in LMICs like Nepal a welcome move

Response from the Majority

- Lack of widespread dissemination of info regarding COVID 19 (Even though, information regarding Covid-19 was disseminated everyday at 4pm)
- PTA Arrangement should be mentioned in policy level to make some amendment in existing policy
- When emergency use drug authorization is done, there is need to explain in detail about the phase-3 trial to the participants

Representative Responses

"I received information through contact person in TUTH. He was the first person to receive the vaccine in TUTH. He reinforced us to receive COVID-19 vaccine, but I was bit anxious as it was new vaccine and register as EUA. Therefore, I consulted with my brother who advised me to receive vaccine. This was how I received COVID-19 vaccine during its pandemic" (GM3). "I got the information from media and went to receive vaccine in the hospital. As I am doctor, it was easy to receive vaccine and health professional were in priority at that time" (GM1). "During that period, I was employed at the college in Itahari. The college facilitated our vaccination process, and the College Administration provided us with information about the vaccine. Additionally, the Itahari ward authorities raise awareness about the vaccine, explaining its uses and advantages before we received the vaccination" (GM8).

Representative Responses...

"We did not sign any informed consent before receiving the medicinal product. However, they provided us with information about the potential symptoms we might experience after receiving the vaccine, such as nausea and weakness. Additionally, there was a waiting room where we sat for 10-15 minutes in case of any symptoms or allergies we might feel" (GM1). One of their contrast response was "I was vaccinated from Itahari and I signed an informed consent before being administered the medicinal product"(GM8).

Representative Responses..

"As I have mentioned before, I had to do online entry in case of any adverse event" (GM3). "Following our vaccination, the ward office promptly contacted us for a follow-up three days later via a phone call"(GM6). "No follow-up was done"(common response).

"I have not heard regarding PTA at all, it will be a good thing if it is implemented. But might be difficult in a country like Nepal(IDI).

"It is redundant to have same answers to fill in in the questionnaire when I have already answered the same in the interview (IDI 12)"

Challenges

- Identifying the appropriate participants for both IDIs and FDGs
- Reluctance of some participants for the IDS and FGDs
- Unavailability of International Funders for IDIs
- Some participants trying to dominate during FGD

Conclusion

- Overall a positive impression from the team
- Great learning experience
- Glad to be a part of a larger team working on a needy area