

COR-NTD 2020

Virtual Meeting, November 12 – 14

Integrating for Impact

Participatory Approaches for Programme Equity

Session Date: 11/12/20

Session Time: 11:00 AM - 2:00 PM EST

Session Description: This session aim(s) to:

- Demonstrate and share experiences of using participatory health research methods to address NTD programme challenges, with a specific focus on equity and inclusion.
- Strengthen the skills of the NTD community in using participatory methods and think differently about research design and delivery.
- Establish an operational research agenda that could be addressed through the utilisation of participatory approaches.

Session Chairs: Laura Dean and Irene Jimeno

Session Rapporteur: Kelly Smyth

KEY DISCUSSION POINTS

- Participatory methods can be used for a number of purposes including: to capture and understand realities, to identify problems within the health system, and to collaboratively develop potential solutions to barriers. These methods are a locally situated, and enable a collective research process which promotes transformation through human agency.
- There was a wide range of participatory approaches discussed. These included:
 - Visual methods, such as communication of messages and research findings via cartoons and video. Visual methods can be used to enable successful knowledge translation, explore intervention ideas, facilitate engagement with persons affected by NTDs, and bring research findings to life. Advantages of visual methods include being easily digestible, visually appealing, and that they can be utilized with populations with lower literacy levels. Visual methods help to enable dialogue, fostering open discussions between researchers and implementers- they can also aid the flattening of power hierarchies through the creation of participatory and shared learning environments.
 - Rapid group ethnography- a standardised qualitative approach was developed in response to the gap in availability of qualitative tools in NTD programme assessment. Rapid group ethnography is a local team-based approach with facilitated group analysis that enables data to be processed in real time- rapid results support quick decision making. Local researchers who are engaged in rapid group ethnography can have their capacity strengthened to support



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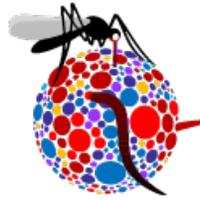
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longevity of the process. A disadvantage of this approach was the professional hierarchies limiting dialogues between researchers and programme implementers.

- Stepping stones participatory method which, in the presented study, sought to understand health care pathways for Female Genital Schistosomiasis (FGS). Through a participant-led scenario exercise, stakeholders encouraged participants to develop their own solutions and identify what is needed to strengthen the health system. Ground rules were set for the sessions to allow for more inclusive discussion. It was found that there is limited awareness of FGS among health care workers, policy makers, and communities. FGS is often misdiagnosed and has associated stigma. Some women and girls missed out on school deworming programmes and praziquantel is not readily available in all primary healthcare facilities.
- Science shop model, whereby stakeholders were involved throughout the process. Studies included the establishment of a community advisory, executive group, and steering group. Video, events, and printed materials were used to disseminate results.
- Crowd-sourced online repository with the objective of harmonised impact evaluation. The online questionnaire and platform for automatic data analysis and visualisation facilitates comparison, self-reflection, and assessment regarding participatory projects with a view to improvements.
- Issues raised from this session included:
 - There is still a long way to go in regards to achieving programme equity. Gender equity is still perceived as a women's empowerment issue. Considering how these methods could be used to address equity challenges within programmes is critical.
 - Professional hierarchies can often limit dialogue. Additionally, power dynamics can interfere with participatory activities which may negatively affect the participation of less senior participants or stakeholders. Negotiating power differentials can be a challenge- for example between officials at local, state/sub-national, and national levels.
 - When it comes to ethics for participatory methods, the iterative approach can be problematic, as projects are not yet planned in full when ethical consent is applied for.
 - In the current environment of a COVID-19 pandemic, face-to-face interaction has been reduced, and participation often needs to be virtual. This can be seen as less effective as visual cues are more difficult to pick up on conference calls and rapport can be more difficult to develop.

KNOWLEDGE GAPS IDENTIFIED

- The gender gap in NTD programmes needs to be addressed – as we approach goals in elimination and control of NTDs, we must look to those who are left behind. For example, there is insufficient research into safe chemotherapy for NTDs for use by pregnant and lactating women.
- There is a gap in the availability of standardised social science tools, particularly in relation to decision making. Frameworks are required to structure research – clear and consistent methodology aids replicability and evaluation; they will ensure sustainability and help translate theory to action. Frameworks should also enable learning and be open to adjustment.



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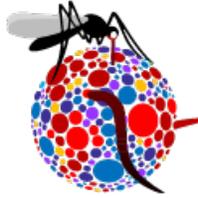
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- There are still significant gaps in understanding the MDA cycles, particularly related to timing – tools developed should address/uncover the barriers and challenges.
- There is a gap surrounding knowledge translation – how can we transfer information gathered through these methods into a practical report for programme managers?
- There are gaps in the skill sets within the National NTD programmes to utilise these methods and consider how they could be used to address equity issues – it is vital to build the capacity of NTD programme managers and researchers at country level to support the use of these approaches.
- There is a gap in knowledge and guidance relating to conducting participatory research virtually in the times of COVID-19. Progress in this area could help in the future, even once the pandemic has ended.
- There is a gap in understanding how to integrate participatory research in NTD programmes. To what extent is the primary structure of NTD programmes amenable to participatory approaches? Since programmes are vertical in nature, how can we push for local-based solutions? Related to this, how can we use participatory approaches to connect the dots between communities and decision making, and imagine new ways of working? Further consideration is needed regarding how we can ‘sell’ participatory research to donors.

RECOMMENDED NEXT STEPS

- Problematise power and hierarchies to facilitate engagement from stakeholders and participants at all levels. Promote use of phrases such as ‘co-researchers’
- Promote capacity building in participatory skills across different sectors.
- Address procedural challenges for participatory research such as difficulties with inflexible ethical approval processes which are more difficult to navigate for iterative approaches.
- Testing of participatory methods and tools and validating against other Monitoring and Evaluation tools.
- Develop research which investigates how to reach marginalised or hard to reach populations, particularly using visual methods. Use participatory approaches for mapping barriers to access, identify site-specific challenges, and to bring non-adherent groups into the fold.
- Integration of participatory methods into NTD programming and measuring or monitoring the impact of NTD programmes.
- Address the gender gap in NTD programming and the barriers to equity.
- Develop frameworks for social science NTD research, particularly participatory research.
- Continue conducting participatory research to aid understanding of MDA and to work with local stakeholders to develop solutions.
- Work with NTD programme partners to promote understanding of participatory approaches.

The below Easy Retro board provides an overview of the key emerging research questions identified in each of the breakout groups:



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Group One (Visual Methods- Shahreen)

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Can visual methods be used to identify novel, site-specific challenges to program uptake?   0  0

Can visual methods be used to bring systematic-non adherent groups into the fold?   2  0

How can visual methods be useful in identifying and mapping barriers to access for different groups of people?   3  0

How can visual methods be used to reach marginalised or hard to reach populations?   13  0

How to use the visual methods to measure or monitor the impact of NTDs programs?   3  0

How can we use to integrate visual methods as a general part of NTD programming? (i.e. the community is often "data heavy" and may not see this as priority)   10  0

Group Two (Seasonal Calendars-(Margaret and Alison))

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Gap in the skillset at the national NTD programme   2  0

Gap in our understanding of how to transfer this information into a practical report for NTD program managers. Gap in our understanding on how to transfer the information   12  0

Testing out these tools in different contexts (diseases, AE) and validating against the more passive M&E tools   10  0

Gaps in our understanding of the whole MDA cycle and the timing and how these tool might address / uncover the barriers / challenges   5  1

Gaps in our understanding on knowledge translation   0  0

Group Three (Participatory Principles-Kim)

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To what extent is primary structure of NTD programmes amenable to participatory approaches?   9  0

How do we 'sell' participatory research to donors?   3  0

How can participatory research be adapted in times of COVID-19?   5  0