

Whose Research Is it? Power, Authority and Voice

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Fig.1 Co-Analysis with peer researchers in Abuja, 2019

In November we travelled to Edinburgh to attend our first UK Participatory Research Network (UKPRN) conference. UKPRN describe themselves as a 'group of people who embrace the philosophy, principles and potential of participatory research'. As our work in COUNTDOWN is grounded in participatory research, this was a wonderful opportunity to meet and learn from other participatory researchers across the UK and share our experiences.

The focus of this meeting was on issues of authority, power and voice in relation to co-analysing data. The meeting began with a presentation by Professor Charlotte Clarke on 'Inciting Dialogue and Disruption' a participatory analysis of the experience of living with dementia'. Co-researchers in this project included people living with dementia and their caregivers. Charlotte's presentation raised many interesting questions on the process of co-analysis, concepts of power, positionality and ethics.

Charlotte's presentation began by describing the principles of participatory research. Participatory research **aims to engage and build relationships with communities whose lives and work are fundamental to the design and analysis of research projects**. It aims to capture multiple perspectives by providing new ways of seeing and thinking.

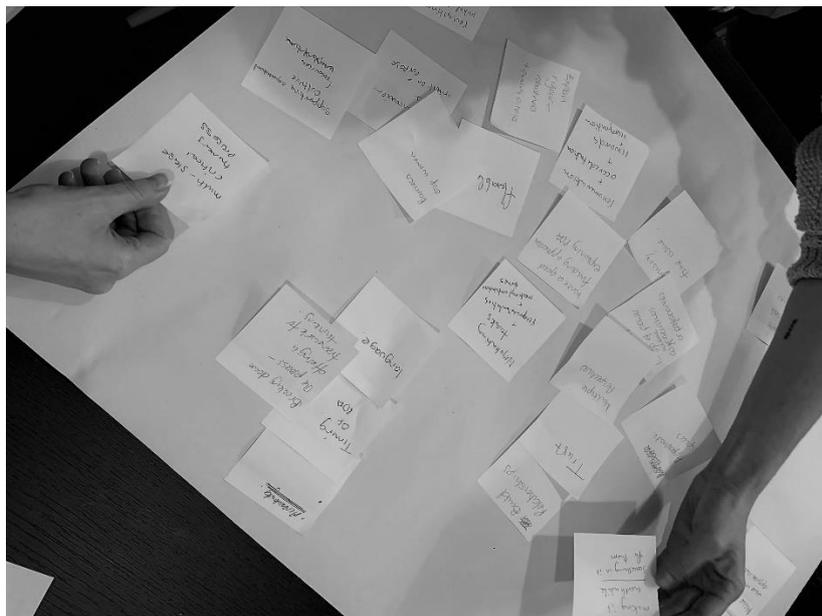
Why is co-analysis needed and who is it for?

Co-analysis is a collaborative process in participatory research where co-researchers analyse the data and collectively discuss and deliberate on what the data tells us. Charlotte Clarke highlighted that participatory research is a way to listen to "silent and silenced voices", and a dialogue on the data through co-analysis enables knowledge democracy, and space for listening and reflection from the vantage point of those who are often more marginalised.

Marginalised groups, such as people living with dementia and disability are often excluded from the research process, especially data analysis. Data analysis is regarded as requiring critical, analytical, and conceptual thinking which many assume that people considered to be vulnerable cannot take part. However, Charlotte highlighted that people with dementia are not a homogenous group and many if not all have skills and abilities that are essential in participatory analysis processes. Moreover, in order to have people centred approaches to health system design,

research processes need to be inclusive. This principle is paramount to COUNTDOWN's philosophy in supporting Neglected Tropical Disease programs to be equitable through promoting the voices of communities affected. However, in order for analysis to be inclusive, it needs to be accessible and creative.

'Out of mess, creativity can emerge' (Tina Cook)



Data analysis was described as being a 'messy state' because the process of analysis requires subjectivity to lift meaning from vast amount of data. While multiple co-researchers will be involved in the process of co-analysis, this often goes back to the academics who then group themes emerged. This inevitably means that multiple voices can become a singular narrative and this dynamic presents questions on who holds the authoritative voice? And whose research is it? In participatory sessions throughout the day, we discussed the ownership of research and the idea that it is for no one to own.

This is why non-textual ways of communicating and analysing data is important. Creative and innovative methods can make research more accessible. In 'Inciting Dialogue and Disruption', performance was used to share and interpret findings to a wider audience. Similarly, COUNTDOWN has aimed to do this through the use of illustrations and videos.

During the day, we were able to share our experiences in participatory approaches within COUNTDOWN. We presented posters on recent projects; a DMDI (Disease Management and Disability Inclusion) study in Nigeria involving co-analysis with co-researchers which included community health workers and people affected by NTDs. We conducted interviews with a Community Health Worker co-researcher ([Isah](#)), case co-researchers ([Amina](#) and [Ibrahim](#)) on their experiences of research and the co-analysis process.

We also reflected on the [Participatory Guide for Planning Mass Administration of Medicines case study in Nigeria](#) and on the importance of also engaging co-researchers within health systems from data collection to analysis to promote health systems strengthening for sustained action.

COUNTDOWN is not alone in deliberating how to engage co-researchers within the entire research process, the [ARISE Hub](#) that works within informal spaces in urban contexts is also having similar dialogue.

We are continually learning and reflecting on the challenges of power, voice and authority and we endeavour to build on these insights within our current research.

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