

## Reflections on using body mapping as a participatory process with people living with lifelong morbidities and disabilities due to NTDs in Liberia

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### Introduction

In 2020, the COUNTDOWN programme launched a COVID-19 Rapid Research Fellowship for junior researchers aimed at supporting innovative research on NTDs and COVID-19 to inform the current outbreak response and preparedness for future outbreaks. The Liberia team being one of the successful countries focused their research on people living with or affected by NTDs, particularly those with life-long morbidities or disabilities, to ensure they can access the support that they need. This study was conducted in Bong and Nimba counties with people living or affected by Buruli Ulcer, Leprosy and Lymphedema.

As part of our innovative research, we used body mapping as a participatory process to engage our participants. Body mapping is a qualitative research method used to obtain a story of a participant that virtually reflects their social, political and economic processes as well as their embodied experiences and meanings ascribed to their life circumstances that shape who they have become (de Jager *et al.*, 2016).

Using participatory body mapping helped participants in our study to explain the experience of living with NTDs visually, and how this has changed during the COVID-19 pandemic.

During the body mapping exercises, the participants were asked to make an anecdote of themselves and were encouraged to indicate key areas/parts of their body most affected by NTDs. This exercise lasted no more than 10-15 minutes during each interview.



Figure 1: One of our study sites in Bong County, Liberia

Many of the participants willingly carried out the exercise with the exception of a few who did not have the ability to draw due to physical limitations, and/or the required literacy level. These participants were willing to be assisted to carry out the exercise. During the process, the interviewer probed further to understand the burden of pain, duration of pain, management of pain and other support services.

### Reflections

Prior to data collection, researchers were contemplating how successful this body mapping would be, due to the sensitive nature of sharing personal information like describing one's disability, however most of the participants were happy to disclose information about their conditions through diagrams and drawings.

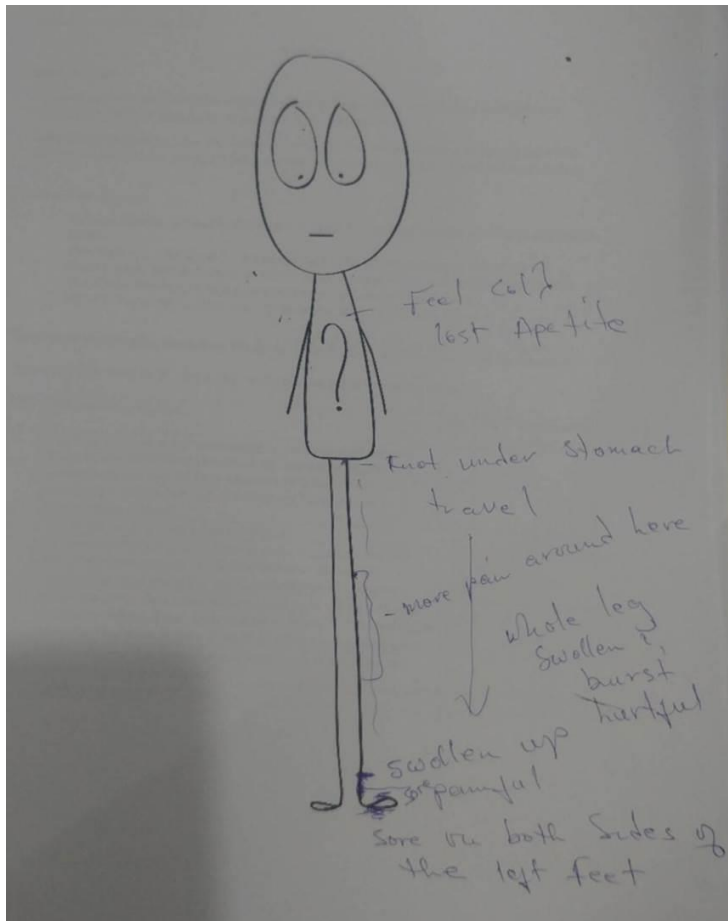


Figure 2: Body mapping with a Buruli ulcer patient

The body mapping exercise allowed participants to be more involved in the research process. It allowed participants to take control by visualizing their own story of what affects or burdens them most, their emotions/feelings and the current state of their wellbeing.

Some of the participants' moods changed during different stages of the body mapping exercise. Some were tense at the beginning but gradually became relieved, contributory, and hopeful while others were excited at the beginning but when the process progressed, they began to get emotional, agitated, and hopeless. Some of the factors that led to these emotions were discrimination, neglect, or lack of support from friends and family members.

Other factors were associated with the COVID-19 pandemic such as observing social distancing which has further kept people apart; and the current economic hardship in Liberia which has resulted in family members and friends reducing support and aid to people with disabilities despite the latter not being able to fully provide for themselves. Figure 2 shows a body that was mapped by a participant with Buruli ulcer.

## Conclusion

Body mapping is useful in gaining access to people's perceptions of their bodies and their personal experiences, particularly how they encounter access to healthcare services. Having visual information can help clarify doubts and create open conversation around ideas and issues which are less discussed verbally and explore particular medical issues (Cornwall, 2001).

The participatory body mapping exercise in qualitative research also enhances the researcher's ability to get the patient or participant involved more with the research. It is a rapport-building initiative that gets the participant's full involvement and enables them to open up in providing more information during an interview, while at the same time motivating them to freely entertain probing questions for details on their condition. In this study, it gave the participants the power and edge to voluntarily translate their emotions/feelings of morbidities and disabilities due to NTDs. This created an open flow of conversation between the researchers and the participants.

## References

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