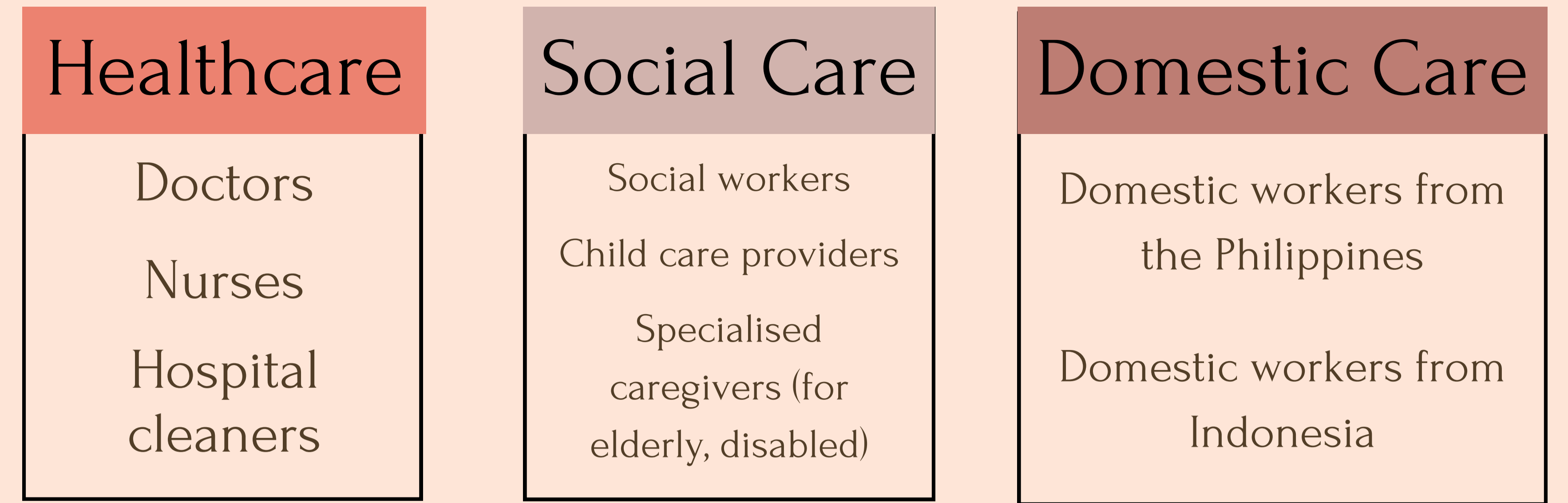


# Challenges of Community Participatory Approaches in Public Health Research to Uncover the Gendered Impacts of COVID-19 on Essential Care Workers

Anis Farid\*, Denise Spitzer\*\*, Shanthi Thambiah\*\*\*, Shazana Agha\*, Abinaya Mohan\*  
 \*Women's Aid Organisation (WAO), \*\*University of Alberta, \*\*\*Universiti Malaya  
 recare@wao.org.my

Figure 1. Groups of those classified in the Project as essential care workers



## 1. SUMMARY

It is essential for community participatory approaches in undertaking a project to understand the gendered impact of COVID-19 on essential care workers to accurately reflect the lived experiences of those impacted. The project employed a participatory approach involving community members as Research Associates trained to conduct focus group discussions in order to better facilitate the involvement of essential care workers as interlocutors and community advocates. This extended abstract highlights two critical challenges with this approach, including translating academic concepts into accessible practical tools, as well as administering and fine tuning modules.

### KEYWORDS

Community, participatory approaches, public health, COVID-19, care work

## 2. INTRODUCTION

The Endemicity, Care, and Gender: Towards Developing Resilience in Malaysia's Care Workforce and Infrastructure (RE:CARE) Project is working to uncover the gendered impacts of the COVID-19 pandemic on essential care workers by examining their paid and unpaid care work burden.

Care work is disproportionately shouldered by women, both professionally and at home. The situation was exacerbated by COVID-19, despite the move towards endemicity. Endemicity, is generally understood as the point where a disease is constantly present but no longer constitutes an active crisis (Samuel, 2022). Essential care workers, including healthcare workers, and their pandemic experience in Malaysia, remains understudied, a blindspot which must be addressed to develop policies to better support Malaysia's essential care workforce and infrastructure. However, the need for data collection practices to centre the experiences of frontliners is crucial.

## 3. METHODOLOGY

To centre the experiences of essential care workers, it was necessary to employ a participatory approach, which is defined as the "co-construction of knowledge through partnerships between researchers and those affected by/involved in the phenomenon under study" (Wilkinson and Wilkinson, 2017).

By centering the perspectives of a diverse range of stakeholders directly impacted by care policies, we shape the research as a collaborative process through partnership(s), recognising and utilising the distinct strengths of the individuals involved. This approach shifts care workers' roles from a 'group under study' to **one actively engaged in the process of developing resilient, inclusive policies**. We are interested in the participation of marginalised communities, such as hospital cleaners, careworkers in rural areas and migrant workers to name a few, who are Research Associates as part of a mutual knowledge-building processes.

This participatory approach was employed in further refining both data collection tools developed and training manuals to equip Research Associates with the skills to implement the project.

## 4. DISCUSSION AND CONCLUSION

Individuals, from the selected essential care worker communities (Figure 1), partook as Research Associates. Their titles were chosen to reflect their role in the research process, not merely as data collectors, but as individuals who actively contribute their perspectives throughout the process.

The initial tools were developed by the research team, consisting WAO and academics from the University of Alberta and Universiti Malaya, and were shared with the Research Associates. Through collaborative discussions, these tools were further refined and a few challenges faced in the process. The key challenges are:

### Challenge 1: Accessible dissemination of academic concepts and knowledge

As rigorous research necessitates adherence to academic protocols, administering data collection methods, such as focus group discussions, in ways that were practical to the essential care worker community required translating concepts not only from English to Bahasa Malaysia, but from academia to practice. Modifications that were made included ensuring that the Research Associates understood the intent of the questions, to allow expression of difficult concepts in ways more easily understood to their community.

### Challenge 2: Capturing unique experiences

Questions from the interview schedule were customised with feedback from Research Associates to reflect experiences of particular communities. For example, with hospital cleaners, they recommended capturing the sanitisation SOP changes as a result of COVID-19 and how to create a data collection tool that better reflected the lived experiences of hospital cleaners.

Translation processes involved community translators to ensure materials were faithful to how the communities' linguistic culture. This resulted in guides created in Bahasa Malaysia, Bahasa Indonesia, and Tagalog.

The approach is unique because research occurs at an intersection between academia, civil society, and community—bringing different perspectives and understanding of care work and the shape it took during COVID-19 and into endemicity. In involving Research Associates who represent their community, the research is more sensitised.

Figure 2. Participatory process flow.



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