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Editorial

Can missing data ever be valuable?

A clear lesson learned during the pandemic reflected that specific populations – notably vulnerable populations – were left out of research and resultant evidenced-based policy and programmatic decision-making and implementation. This missing data can be thought of as valuable since it has assisted in the awareness of the need for researchers and scientists to navigate an area that is commonly underserved – collection of disaggregated data among vulnerable populations.

There has been a plethora of lessons learned during the Covid 19 pandemic. From a public health perspective; researchers, scientists, implementors and front-line workers have learned to pivot rapidly and adjust. While adjusting to the new, and ever-changing situation, a key area was often the most overlooked – research data to guide evidence-based decision making. These chasms of missing data, notably disaggregated data, demonstrated health disparities among vulnerable populations.

The gap in disaggregated data has highlighted that factors such as gender, age and disability are all glaringly deficient. Research, services and funding cannot adequately reach populations if data is not present. How can disaggregated data help fill in research gaps – especially those highlighted during a pandemic? Firstly, there is a need to identify who fell between the cracks, who is at risk of falling and how can we create a bridge over the gap. Secondly, there is a significant need to create an awareness of why disaggregated data is needed for a better response. While this focuses on the current Covid 19 pandemic, it can be translated to any public health situation. According to the Pan American Health Organization (PAHO), high quality, accessible, trusted, timely, open, and reliable disaggregated data is critical to generating valuable information for decision-making in real time. Not only did the Covid pandemic worsen inequalities for under-represented and vulnerable populations, it highlighted that data is often exclusive and generalized.

One of the gaps identified during the pandemic demonstrated that various (notably vulnerable) populations were affected differently, however, data that had been collected in a purposeful, inclusive, multi-dimensional manner – to better understand age, sex, geographic area, education, ethnicity, disability, and other variables related to health disparities was non-existent or limited at best.

This gap in data left many pandemic responses scrambling to make (often uninformed) decisions on how to best allocate resources and reach all populations. An end result of the research related to the Covid 19 pandemic was the light that was shed on the crucial need for disaggregated data with meaningful participation of those most affected. In this way, future pandemics, public health emergencies, and programs can benefit from informed, evidence-based policies and practices driven by rigourous research data.

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