

## COVID COLLECTIVE PROJECTS FROM AROUND THE GLOBE

### Disability and Covid-19 in Vietnam

→ Vietnam

→ LSHTM and Hanoi University of Public Health

People with disabilities are frequently overlooked in research, which contributes to their marginalisation in policy, programming and everyday life. Through triangulating quantitative and qualitative data, this project aimed to bring visibility to this too often invisible group in Vietnam. Widely praised for its successful early containment of Covid-19, Vietnam's rigorous containment measures had significant social and economic consequences, particularly for people with disabilities.

### African Cities and Covid-19 – Learning and Building Knowledge: Developmental Coalitions in Informal Settlements

→ Kenya, Uganda, Somalia

→ University of Manchester Global Development Institute (GDI)

Three local research teams in Nairobi, Kampala and Mogadishu set out to understand how the pandemic and local pandemic responses disrupted everyday life for the majority and often poor households in these settings. In addition to generating valuable and rich local evidence, the project led to collective action and new collaborations between state and non-state actors.

### Strengthening Advocacy and Mobilisation on the Frontlines: Action-Research to Address Covid-Related and Other Risks in Mathare, Nairobi

→ Kenya

→ Mathare Social Justice Centre (MSJC) Slum Dwellers International-Kenya (SDI-K) International Institute for Environment and Development (IIED)

Putting communities at the heart of knowledge production through action research was the approach taken by this project which worked with people and grassroots organisations in informal settlements in Mathare. They co-produced evidence on the struggles residents faced to observe Covid-19 prevention measures and maintain precarious livelihoods, among contending with other challenges like political exclusion. The findings have supported advocacy for more equitable and inclusive governance.



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This brief aims to provide rapid syntheses of a selection of recent relevant literature and international expert thinking in response to specific questions relating to international development. It was written by Tabitha Hrynick, Researcher at the Institute of Development Studies, and commissioned through the Covid Collective.

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Find out more about the Covid Collective [www.covid-collective.net](http://www.covid-collective.net)

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The Inclusive Growth in Mozambique programme has undertaken since 2021 an enterprise survey throughout the country to analyse the development of enterprises, including an analysis of the dynamic factors and constraints faced by these companies. © UNU-WIDER, CC BY-NC 2.0; Lucy Milmo/DFID via BIGD website



## COVID COLLECTIVE KEY ISSUE GUIDE:

# Data, knowledge and information



# Summary

Co-production [of knowledge] is a sharing of power, with stakeholders and researchers working together to develop the agenda, design and implement the research, and interpret, disseminate, and implement the findings. (Redman *et al.* 2021)

This briefing summarises key issues identified by Covid Collective partners and academic literature around data, knowledge and information in the context of the Covid-19 pandemic response and recovery, and a sustainable, equitable future.

**Social knowledge is critical.** While there has been a strong emphasis on evidence-based decision-making during the pandemic, reliance on expert-generated public health and biomedical knowledge proved insufficient. This narrow focus exacerbated inequalities and highlighted the need to incorporate social science evidence, and diverse forms of knowledge co-produced by a greater range of stakeholders, including communities.

**Utilising existing data.** Significant amounts of data and evidence already exist, but challenges hinder their utilisation for equitable recovery and sustainable futures. Knowledge sharing between stakeholders remains limited, with community-level actors being particularly excluded. This has led to wasted or duplicated data, damaged trust and ultimately hampered effective action.

**Data gaps persist.** Additionally, huge knowledge gaps remain, especially in the Global South, and regarding vulnerable groups, perpetuating marginalisation. To address this, context-sensitive qualitative and participatory knowledge approaches that involve marginalised communities in knowledge creation are essential.

**Ethics in knowledge production.** Stigmatisation of marginalised groups can occur through data collection and communication practices, and trust eroded when only well-connected individuals are engaged. Concerns over surveillance and privacy breaches can arise. Informed consent, dignity, rights, privacy, and inclusion should be central to knowledge creation, with the direct involvement and leadership of local people.

**Need for more collaboration and co-production.** Beyond data sharing, meaningful collaboration and inclusive knowledge co-production between diverse stakeholders is urgently needed. Communities in particular should be supported to build not only their technical knowledge production capacities and to engage in broader initiatives, but empowered to effect change. Both new and traditional approaches to knowledge processes, including digital technologies and indigenous knowledge techniques, should be embraced for inclusive and comprehensive approaches.

## Key Issues

### Diverse knowledge is critical to effective, equitable response and recovery

Despite newly reinvigorated and widely embraced calls for 'evidence-based decision-making' and lessons from previous global health crises, expert-generated epidemiological, public health and biomedical knowledge was the dominant form of knowledge throughout the Covid-19 pandemic (IDS, 2023). Yet, as much of the Covid Collective research projects showed, this was not enough to contain Covid-19, nor account for diverse and dynamic social, political and economic complexities. This narrow focus resulted not only in the continued spread of Covid-19, but in profoundly deepened social and economic inequality and marginalisation of the most vulnerable. This has reinforced the importance not only of social science evidence and data to effectively and equitably address, recover and prepare for complex challenges like pandemics (alongside quantitative and public health evidence) but of diverse forms of knowledge co-produced by communities as well as experts (ibid).

### A lot of data and evidence already exists

Although social knowledge has been largely marginalised in the pandemic, particularly in the early days, much data has been generated as researchers, civil society, governments and others mobilised to generate it. A lot of relevant knowledge also predated the pandemic. However, key challenges stood – and continue to stand – in the way of existing knowledge being utilised for a more equitable (and effective) Covid-19 response and a sustainable and equitable future. A critical barrier identified by Covid Collective partners is a lack of collaboration and data sharing between stakeholders across sectors (e.g. academic, government, civil society etc.), organisations and levels, with community-level actors being particularly excluded in three key ways: 1) not having critical knowledge shared with them; 2) their knowledge and expertise being ignored; and 3) not being supported to increase their own knowledge production capacities.

This lack of integration also results in unhelpful duplication of data efforts – including fatigue and disillusionment among communities where data is repeatedly collected by different stakeholders. Questions around the quality of existing data – also related to collaboration failures – also pose barriers to its usefulness when it comes to responding to and recovering from complex crises and building more equitable societies.

### Knowledge gaps persist on vulnerable groups

While it is important for stakeholders to join up efforts to make better use of existing data, there remain major knowledge gaps. This is the case on a global scale (despite being the majority of the world, data on the Global South is scarcer than data on northern contexts), as well as on national and local scales, particularly in relation to the lived experiences, challenges, priorities, perspectives and capacities of vulnerable groups (Milan and Treré, 2020). Such groups might include people with disabilities, elderly people, displaced people, seasonal migrants, informal labourers, informal settlement residents, low-income or unemployed people, ethnic and religious minorities, and sexual and gender minorities, women and children among these cohorts, among other groups who may be vulnerable in particular local contexts, many of which, Covid Collective partners have engaged and co-produced knowledge with (Keo *et al.*, 2022; Lippman *et al.*, 2022; Zaman *et al.*, 2021).

The invisibility of vulnerable people and communities in data, knowledge and evidence perpetuates their continued marginalisation as crisis response and recovery measures, policies and programmes do not take their realities and needs into account. Even worse, crisis narratives, reinforced by poorly designed data collection and communication can endanger vulnerable groups by blaming them for causing crises (Leach and Tadros, 2014). The specific realities of those at the margins are by definition lost in 'big data.' This necessitates more sensitive qualitative approaches and participatory methodologies which include marginalised people in knowledge creation to achieve effective and just recovery from the Covid-19 pandemic and a sustainable future (Wheeler *et al.*, 2017).



### Ethics of data collection and knowledge production

Another key issue to consider is the importance of ensuring data collection and knowledge production processes are ethical, and protect and respect all involved. As noted, how data is collected or communicated can further stigmatise marginalised groups (Leach and Tadros, 2014). Local people may also grow weary and suspicious of repeated visits by outside data collectors to extract information and fail to feedback their findings, or leverage their research efforts for local change. Trust – and the quality of evidence – may also be lost when only the well-connected are engaged. People in many contexts may also have reason to fear surveillance and breach of privacy. Informed consent, dignity, rights, privacy and inclusion – including the direct involvement and leadership of local people – are central issues to knowledge creation.



## Emerging Lessons

A number of emerging lessons have been identified by Covid Collective partners, which also echo key lessons outlined in literature.

### More data-sharing, collaboration and co-production is needed

A Thai health leader once described collaboration between government, people and academia as a 'triangle that moves mountains' (Tangcharoensathien *et al.*, 2021). Greater collaboration between sectors, disciplines and scales is needed more than ever in our increasingly complex world (Redman *et al.*, 2021). Such collaboration should aim to foster not only data sharing across these lines, but synergistic and equitable co-production and empowerment for change between diverse stakeholders (Norström *et al.*, 2020; Apgar *et al.*, 2016). It should enable inclusive discussion that identifies and aims to fill knowledge gaps while avoiding duplication, monitor data over time, and support greater accuracy, comprehensiveness, transparency, ethical and inclusive practices, and appropriate communication of knowledge, tailored for different audiences.

### Greater commitment to equity, ethics and trust is needed

To achieve a more equitable world, greater attention is needed to fill knowledge gaps. This includes rectifying scarcities of data in Global South contexts linked to modes of coloniality which have marginalised southern researchers, and southern knowledge systems (Taylor and Tremblay, 2022). That said, the Covid-19 pandemic seems to have provided opportunities for southern researchers more (Lenhard, 2021), and momentum to support this must be maintained. Data gaps are also prevalent among vulnerable communities. This must go hand in hand with an ethical approach which embeds dignity, rights, privacy, and inclusion into data collection, analysis, communication and feedback processes.

Community members should be involved and centred in these efforts. Trust can be fostered through these commitments and actions, as well as by being very clear about the purpose of data collection, working closely with trusted local networks and people, such as religious leaders and community organisations, and ensuring communities receive feedback. What is the most effective practice differs from context to context.

### Increase the data capacity of communities

Local communities have produced valuable knowledge and evidence throughout the pandemic (McGowan *et al.*, 2022), as shown by much of the work of the Covid Collective (Kimari *et al.*, 2022; Haque *et al.*, 2021). Literature indicates the 'high reliability' of people deeply embedded in and sensitive to systems, making them experts whose knowledge is critical for responding to uncertainty inherent in crises (Tasker and Scoones, 2022). Communities must be further supported to build their technical and political skills not only around systematic data collection and knowledge production, but also its communication and use in advocacy for change (Apgar *et al.*, 2016). Supporting community-led action-research, and community inclusion and leadership in broader knowledge and policy production processes can help bridge the gap between the dominance of 'big data' – such as that used to track progress on the SDGs – with local realities and address the needs of vulnerable groups.

### Embrace both new and traditional approaches

Existing and emerging digital technologies can support with data collection efforts (Samadder *et al.*, 2022), especially in situations limiting in-person connection (Strachan, 2021). Yet, digital divides are still a reality in many settings. Efforts continue to be needed to both increase access to such technologies, and to enhance the skills of diverse stakeholders to create, analyse, share and access data and information. At the same time, traditional face to face and pen to paper approaches, as well as indigenous and creative modes of knowledge creation and sharing should continue to be embraced to foster inclusive, comprehensive and decolonial approaches.

