

# IDS Bulletin

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## **PANDEMIC PERSPECTIVES: WHY DIFFERENT VOICES AND VIEWS MATTER**

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# Adapting Disability Research Methods and Practices During the Covid-19 Pandemic: Experiences from the Field<sup>\*†</sup>

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**Abstract** People with disabilities are often excluded from research, which may be exacerbated during the ongoing Covid-19 pandemic. This article provides an overview of key challenges, opportunities, and strategies for conducting disability-inclusive research during the pandemic, drawing on the experience of research teams working across ten countries on disability-focused studies. It covers adaptations that are relevant across the project lifecycle, including maintaining ethical standards and safeguarding; enabling active participation of people with disabilities; adapting remote research data collection tools and methods to meet accessibility, feasibility, and acceptability requirements; and promoting inclusive and effective analysis and dissemination. While this article is focused on adaptations during the pandemic, it is highly likely that the issues and strategies highlighted here will be relevant going forward, either in similar crises or as the world continues to move towards greater digital communication and connectedness.

**Keywords** disability, inclusion, ethics, Covid-19, research practices, accessibility.

## 1 Introduction

The ongoing Covid-19 pandemic has brought disruptions to all spheres of life, including research. Notably, in-person data collection – a common practice for social science research

pre-pandemic – has often not been possible or has had to be altered given restrictions on movement and face-to-face meetings (Lupton 2020; Rohwerder *et al.* 2021b; Wickenden *et al.* 2021b). However, social science research is critical to understand the implications of the pandemic on people's lives and to inform policy and planning.

Research must be inclusive of people with disabilities, who constitute approximately 15 per cent of the world's population depending on the methods used (Loeb, Eide and Mont 2008; WHO and World Bank 2011). People with disabilities are defined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as including 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (OHCHR 2006: 4). Pre-pandemic, people with disabilities faced systemic barriers to inclusion in areas such as education, health, employment, and social participation (UN 2019). Existing evidence indicates that the direct and indirect impacts of the pandemic may have widened these inequalities (Brennan 2020; Rohwerder *et al.* 2021a; Shaw *et al.* 2021; Thompson *et al.* 2021; Wickenden *et al.* 2021a, 2021b).

People with disabilities have often been underrepresented in research even before the added challenges brought by the pandemic (Yeo and Moore 2003; Groce and Mont 2017). Studies conducted during the pandemic have highlighted additional challenges in collecting data on disability during the pandemic, including concerns about the accessibility of technology and tools for remote data collection, recruiting hard-to-reach populations, and maintaining ethical standards, particularly for studies on sensitive topics (Brennan 2020; Wickenden *et al.* 2021b). Without concerted efforts, the pandemic risks further excluding people with disabilities from research, which means their experiences and concerns may not be reflected in outputs designed to inform policy and planning.

Consequently, this article will explore the critical question of how to adapt disability research methods and practices during the pandemic. It will consider how research teams can adjust to Covid-19 regulations and restrictions, including adaptations needed for different subgroups (e.g. by impairment type, children vs adults) or different research focuses (e.g. involving sensitive topics).

The remainder of this article is as follows. Section 2 describes the underlying research studies that ground the learnings of this article. Section 3 discusses the overarching principles of disability research. The next three sections explore the challenges of and strategies for inclusive research during the pandemic including upholding ethical standards (Section 4), adapting data collection (Section 5), and ensuring inclusive and effective analysis and dissemination (Section 6). Section 7 provides concluding remarks.

## 2 Background to this article

This article draws on the experience of several teams conducting research with people with disabilities during the Covid-19 pandemic in the UK, South Africa, Zimbabwe, India, Zambia, Bangladesh, Turkey, Cambodia, Vanuatu, and Ghana (see Table 1). These studies represent a diversity of settings and research questions, although the study designs were primarily qualitative. They also reflect a range of adaptations made in response to different Covid-19 restrictions in place at the time of data collection. Research teams, including team leads and multiple authors on this article, included people with disabilities. Although all included studies were disability focused, the learnings from the research teams could be applied to non-disability-focused studies as well.

**Table 1 Overview table of studies led by authors**

Country (project)	Study topic	Participants	Study design	Date of data collection	Covid-19 restrictions in place at the time of data collection
<b>South Africa</b> (Forgotten Agenda)	Sexual and reproductive health and rights under Covid-19	Women aged 18–25 with and without disabilities (impairment types: physical, sensory, and intellectual)	Longitudinal case studies applying mixed methods including PhotoVoice,* series of interviews collecting qualitative and quantitative retrospective and prospective data	July–September 2021 (further rounds planned)	Varying levels of restrictions included stay-at-home orders, compulsory mask-wearing, social distancing, and restrictions on social gatherings; additional civil unrest and several full team isolation events.
<b>South Africa</b> (Stroke care services in the South African public health system)	Preferences and experiences of people with stroke of stroke care in South Africa	People with disabilities linked to stroke (adults 18+ years, 24 months post-incident)	Qualitative, in-depth interviews (conducted in person and remotely)	August–October 2020	National lockdown, movement restrictions, closure of schools and non-essential businesses, mandatory mask-wearing, social distancing, limitations on social gatherings.
<b>Turkey</b> (Covid-19 and disability study)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (all ages, physical, sensory, intellectual/ cognitive, and psychosocial impairments)	Qualitative, in-depth interviews (conducted remotely)	May–August 2021 (further rounds planned)	Mandatory mask-wearing in public indoor and outdoor spaces, social distancing.

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**Table 1 Overview table of studies led by authors (cont.)**

Country (project)	Study topic	Participants	Study design	Date of data collection	Covid-19 restrictions in place at the time of data collection
<b>Bangladesh</b> (Covid-19 and disability study)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (ages 10+, physical, sensory, intellectual/ cognitive and psychosocial impairments)	Qualitative, in-depth interviews (conducted remotely)	April–August 2021	Nationwide lockdown, mandatory mask-wearing to receive services, border closures, police presence/fines enforced restrictions, closure of schools and non-essential businesses.
<b>Ghana</b> (Covid-19 and disability study)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (all ages, physical, sensory, intellectual/ cognitive, and psychosocial impairments)	Qualitative, in-depth interviews (conducted in person and remotely)	May–July 2021 (further rounds planned)	Mandatory mask-wearing (indoor and crowded outdoor spaces), closure of some non-essential businesses (e.g. clubs, cinemas), limits on large social gatherings.
<b>UK</b> (Covid-19 and disability in the UK)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (all ages, physical, sensory, intellectual/ cognitive, and psychosocial impairments)	Qualitative, in-depth interviews (conducted remotely)	Round 1: June–August 2020  Round 2: February–April 2021	Round 1: mandatory mask-wearing in indoor spaces, social distancing (meetings of up to six people); gradual easing towards July.  Round 2: national lockdown, movement restrictions, closure of schools and non-essential businesses, mandatory mask-wearing in indoor spaces, strict social distancing (no indoor meetings outside of household/support bubble; outdoor meetings only for exercise with one other person not in household/support bubble).

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**Table 1 Overview table of studies led by authors (cont.)**

Country (project)	Study topic	Participants	Study design	Date of data collection	Covid-19 restrictions in place at the time of data collection
<b>Cambodia and Bangladesh</b> (Translating disability-inclusive WASH policies into practice)	Inclusion of disability in water, sanitation and hygiene (WASH) policies and practice	People with disabilities (>18 years, physical, sensory, intellectual/cognitive impairments) and caregivers	Qualitative, in-depth interviews (conducted remotely in both countries)	Cambodia: February–July 2021  Bangladesh: August 2021–present	National lockdown, movement restrictions, closure of schools and non-essential businesses, mandatory mask-wearing, social distancing, limitations on social gatherings, face-to-face business meetings banned in both countries.
<b>Vanuatu</b> (Shifting humanitarian norms)	Exploring the menstrual health experiences of people with intellectual impairments in a humanitarian context	People with intellectual impairments (15–24 years) and caregivers	Qualitative, PhotoVoice and ranking, observation, in-depth interviews (conducted in person)	October 2020–March 2021	Vanuatu's borders closed, no restrictions within the country outside encouragement to follow hygiene and social distancing practices.
<b>Zambia</b> (PENDA PhD research)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (all ages, physical, sensory, intellectual/cognitive, and psychosocial impairments)	Qualitative, in-depth interviews (conducted remotely and in person)	July–November 2021	Mandatory face masks in public settings, closure of schools and non-essential businesses, restrictions on large social gatherings.
<b>India</b> (Covid-19 and disability study)	Experiences of people with disabilities during the Covid-19 pandemic	People with disabilities (all ages, physical, sensory, intellectual/cognitive, and psychosocial impairments)	Qualitative, in-depth interviews (conducted remotely)	December 2020–March 2021 (further rounds planned)	Movement restrictions, mandatory mask-wearing, school closures, restrictions on social gatherings.
<b>Zimbabwe</b> (Building back better)	Access to health among people with disabilities	People with disabilities (all ages, physical, sensory, intellectual, and psychosocial impairments)	Qualitative, in-depth interviews (conducted in person)	May–June 2021	Mandatory mask-wearing (indoor and crowded outdoor spaces), closure of some non-essential businesses (e.g. clubs, cinemas), limits on large social gatherings.

Note \* PhotoVoice is a qualitative and participatory research methodology, in which participants are asked to use photography to demonstrate their point of view or experiences in relation to a research question.  
Source Authors' own.

### 3 Applying overarching principles of disability research

There is a growing literature predating the pandemic describing how to conduct research with people with disabilities that is inclusive, ethical, robust, and relevant to different contexts (Shakespeare 1996; Barnes and Mercer 1997; Oliver and Barnes 2010; Mji *et al.* 2011; Owusu-Ansah and Mji 2013; Kyegombe *et al.* 2019). 'Nothing about us, without us' is an overarching principle of disability research, underscoring the necessity of meaningful participation of people with disabilities throughout the research project lifecycle (Charlton 1998). This participation, at a minimum, should include consultations with people with disabilities and disabled people's organisations/organisations of persons with disabilities (DPOs/OPDs) and, where possible, involvement of people with disabilities in the research team. Involvement of and leadership by people with disabilities in research processes is not only in line with a human rights approach (*ibid.*; Smith-Chandler and Swart 2014), but improves the quality and external validity of findings (Rios *et al.* 2016; Kuper *et al.* 2020).

Research on disability must also support the direct involvement of people with disabilities as research participants. Involving caregivers either for supplemental information or as a core part of the research study can be helpful depending on the research question (Richardson and Laird 2013; Zuurmond *et al.* 2019), but in most instances should not serve as a substitute for direct participation of people with disabilities. In some cases, caregivers may have to give proxy consent or interviews for children, adults with severe intellectual impairment, and those who cannot communicate with available accommodations (Kyegombe *et al.* 2019).

However, participants with disabilities must be given the opportunity to speak for and represent themselves as much as possible. Supporting direct input may require adaptations to research methodology or ethical protocols and training of data collectors. For example, data collection tools and methods, informed consent procedures, and research outputs must be made accessible (e.g. sign language, easy-to-read formats, screen reader compatibility, held in physically accessible venues) (Wickenden and Kembhavi-Tam 2014; Kyegombe *et al.* 2019; Rohwerder *et al.* 2021b). Further, data collectors must be trained and have a clear protocol for establishing the capacity to consent, in line with national definitions of legal capacity (where available) (Kyegombe *et al.* 2019).

Disability may also overlap with other characteristics that require consideration in the study design. For example, children with disabilities may require support due to both age and disability (e.g. child- and disability-friendly data collection tools, caregiver consent and disability-inclusive child assent procedures, child safeguarding protocols with referrals to accessible services) (Zuurmond, Mahmud and Hartley 2018; Kyegombe *et al.* 2019).



Meanwhile, additional ethical standards – such as researcher training to minimise risks, protection of participant privacy and confidentiality, and development of referral pathways – need to be implemented for vulnerable subgroups that face double or triple marginalisation (e.g. women with disabilities who live in poverty, people with disabilities who are ethnic or religious minorities) and on sensitive topics (van der Heijden, Harries and Abrahams 2019; Wilbur *et al.* 2021).

It is essential to continue following these principles, although adaptations have often been needed during the pandemic and other crises. The following sections discuss our experiences addressing the challenges and opportunities of conducting disability research during the pandemic.

## **4 Upholding ethical standards in inclusive research during the Covid-19 pandemic**

### **4.1 Balancing risks and benefits of remote vs in-person data collection**

Many national Covid-19 regulations have prohibited or discouraged face-to-face meetings, which affected most of the research projects. In addition, even where local regulations allowed in-person meetings, researchers had to consider that some underlying health conditions and characteristics common among people with disabilities are associated with an increased risk of severe Covid-19 disease (e.g. older age, Down's syndrome, presence of chronic conditions, diabetes) (Williamson *et al.* 2021). Therefore, the research teams had to carefully balance the risks and benefits of in-person meetings, taking into account shifting national Covid-19 guidelines; risks to the study participants and research team, including risk of severe Covid-19 outcomes given the specific study population; and coverage of vaccination among the study population.

Researchers also had to assess the feasibility of remote data collection, which included considerations of coverage of mobile technology in the study population; sensitivity of the research topic; participants' preferences; and ability to provide needed accommodations. In projects based in Ghana and South Africa, mixed approaches were used: while many meetings were conducted remotely, people who lacked access to needed technology or faced accessibility or safety concerns with remote meetings were interviewed in person once it was safe to do so.

When in-person meetings were possible, researchers had to implement precautions for the research team and participants. These precautions included providing personal protective equipment (PPE) to the research team, study participants, and their households in all settings that had in-person data collection. Vaccination and regular testing of the research team is an important strategy to minimise risk. However, in many settings, these services were not available at the time of data

collection. PPE also had to be adapted in some cases, such as for participants using lip-reading to communicate. Adaptations in Ghana and one of the South African studies included using clear face shields or having interviews behind a transparent barrier.

#### 4.2 Adapting informed consent in remote research

Choosing remote approaches required adaptations to the informed consent process. Typically, written informed consent is the preference of ethical review boards; however, given the shift to remote data collection, recorded oral consent was permitted by most of the ethics boards. In the South African study on sexual and reproductive health (SRH), written consent was required by the ethics board, but permission was granted to use WhatsApp to obtain it.

Both forms of informed consent had to follow ethical standards of confidentiality, non-coercion, and providing complete information of the study purpose, risks, and benefits. Adaptations were needed to meet these standards and to ensure that processes accounted for both impairment-specific accessibility needs and participants' access to and familiarity with needed technology.

Previous studies have noted that determining capacity to consent is complex and not always clearly defined in national laws and ethical review board protocols (Iacono and Murray 2003; Kyegombe *et al.* 2019), and that checks are needed to ensure adaptations such as easy-to-read formats actually lead to the acquisition of the required information (Hurtado, Jones and Burniston 2014). Determining capacity to consent was further complicated with remote data collection. For example, providing some adaptations to the consent process, such as sign language interpretation or use of easy-to-read information sheets with pictures, was challenging when participants only had standard phones without video or image capabilities, which was common in many settings.

Further, almost all projects reported instances of gatekeeping, in which the listed contact was for another household or family member who prevented direct communication with the person with a disability. Data collectors were instructed to always assess an individual's capacity to consent for themselves rather than rely on the reports of others; however, this was not possible in some instances when the point of contact refused to allow the person with a disability to talk to the researchers.

Deciding on how much information to provide caregivers and the use of proxies was more complicated for sensitive topics. There were concerns that the process of seeking consent or describing the study to a caregiver could breach confidentiality or result in harm to the participant; for example, for studies on violence, if the caregiver was a perpetrator or participants were recruited through services or programmes that caregivers were unaware of.

Consequently, training was provided to data collectors on how to engage with caregivers if they were present. Case studies were used to illustrate when and how to identify appropriate proxies and implementing principles to support decision-making.

Familiarity with needed technology also presented a challenge to the informed consent process. For example, some participants faced difficulties filling in written consent forms sent via email because they did not have or were unfamiliar with software for viewing PDFs, could not add signatures, or simply did not have emails. In the South African SRH study, which required written consent, WhatsApp chat was used in some instances to obtain written consent as at least young people were more familiar with this application.

#### **4.3 Maintaining confidentiality and referral pathways**

With remote data collection and Covid-19 regulations (e.g. lockdowns), many participants took calls from their homes, making it difficult or impossible to maintain privacy from other family members. For example, the study in Turkey focused on Syrian refugees. Many participants in Bangladesh (Covid-19 study) were recruited from informal settlements. In these and other settings, participants often lived in crowded homes where few people had separate rooms or spaces to take a private call.

These limits on confidentiality were especially challenging for sensitive topics (e.g. sexuality or gender-based violence). Even discussing disability could carry risks for the participant. For example, research teams in several project sites reported needing to be cautious in asking questions about a person's impairments when they were not in a private space due to the risk of accidental disclosure to others of conditions that were not always visible but were highly stigmatised (i.e. psychosocial impairments).

Consequently, research teams had to adapt their methods to enable some degree of sensitive data collection. For example, in the South African SRH study, the team asked questions on sensitive topics that the participant could answer with yes/no and then could opt to provide more details if they were comfortable and in a private enough space. This approach enabled some degree of data collection on sensitive topics. Still, it held the potential for breaches in confidentiality should the participant be overheard when providing more detailed information. Similarly, in most settings, participants were first asked to describe their disability or health conditions themselves in order to choose the labels they were comfortable being identified with.

Although not used in any included studies, other projects have used 'quick exit' buttons to shut down websites and applications if there is a breach of privacy. However, the accessibility of these measures is not known (National Network to End Domestic

Violence n.d.). Still, even with these adaptations, monitoring confidentiality was more challenging with remote data collection. It was guided by the participant's comfort in the absence of directly observing who was present during interviews.

Furthermore, ensuring appropriate referrals was affected by disruptions in services (e.g. counselling, protective services) due to the pandemic in both these and other study settings (Brennan 2020). One South African study employed counsellors within the research team to address these challenges who developed new procedures for remote counselling, referral pathways, and follow-ups. Similarly, in Turkey, Zimbabwe, and other settings, researchers compiled a list of available and accessible services operating during the pandemic and contacted them to identify a named point-person.

## **5 Adapting to data collection challenges during the pandemic**

### **5.1 Choosing and adapting platforms for remote data collection**

Remote data collection was used in almost all settings for at least some of the data collection. It was the only option in several sites given project timelines and the Covid-19 regulations and infection rates at the time. The feasibility and acceptability of remote data collection – and which technology to use (e.g. phone, video calls such as Zoom, WhatsApp) – varied by setting, impairment type, age, and mobile phone literacy.

A significant challenge for remote data collection was the lack of access to needed technology. Access to mobile phones and the internet is generally lower among people with disabilities than people without disabilities (UN 2019). Even in the UK, national data from 2018 found that 56 per cent of non-internet users were people with disabilities (ONS 2019).

Older adults with disabilities, people with disabilities living in poverty and in remote areas, and people whose impairments affect the use of standard mobile technology (e.g. people with hearing or intellectual impairments) are particularly at risk of exclusion; other studies have noted the poor availability of needed technology among migrants and homeless populations (Nind, Meckin and Coverdale 2021). For example, many settings reported that participants could access a basic phone. Much fewer had smartphones or computers and strong enough internet/network connections to support video calls. A video connection was essential for people who are Deaf and communicate by sign language. Similarly, having a device that could receive images was needed to support some people with intellectual impairments. Further, some people, particularly older adults, had an internet connection or smartphone within the home but needed support using it. Finally, phone data was costly in several settings, which affected both data collection and recruitment.

Participants' preferences were also a key consideration. Most participants in the UK reported that they preferred or were at least neutral about remote vs in-person data collection, with some pointing to benefits such as reduced travel and more control over the interview process (i.e. ability to leave interviews easily). Some participants with autism or other neurodiversity preferred email to either in-person or Zoom/telephone interviews. In contrast, many people who were Deaf preferred face-to-face meetings to better read sign language. WhatsApp was a popular choice in India, South Africa, and other settings. It is widely used among young people, allows for video calling with multiple people and sending pictures, has safety features (e.g. end-to-end encryption), and low data usage to reduce costs. Standard phone calls were primarily used in Ghana, Turkey, Cambodia, and Bangladesh due to the participants' limited access to other technology.

## 5.2 Recruiting the needed sample

Remote data collection carried both challenges and opportunities for recruitment. It increased the geographic reach in settings such as the UK and Bangladesh (Covid-19 and disability study) to rural or remote areas that would have been logistically and financially difficult to reach with in-person meetings. However, there were trade-offs in that selected participants had to be reachable through a phone or other form of remote technology, which as described above likely led to the underrepresentation of people with disabilities living in poverty, in areas with poor internet/phone coverage, and with certain impairments (e.g. profound hearing loss, intellectual impairments). Other studies have similarly noted recruitment challenges during the pandemic, such as for migrant and homeless populations (Nind *et al.* 2021).

Sampling strategies had to be adapted for remote data collection during the pandemic because house-to-house or similar in-person approaches were not possible in settings with stricter restrictions. In some instances, such as in Bangladesh (Covid-19 study) and Zambia, participants were recruited through previous population-based surveys that included questions on disability (e.g. Washington Group Short Set) and permission to contact participants for further research, as well as through non-governmental organisations (NGOs) and DPOs/OPDs.

However, most included projects used purposive recruitment through DPOs/OPDs, NGOs, community-based leaders, peer networks, or social media. For example, participants were recruited through DPO/OPD networks in the UK, Cambodia, Bangladesh, Turkey, and other settings. In Ghana and the South African SRH study, snowball sampling was used whereby seed participants were identified through DPOs/OPDs and other sources. These seeds then recruited other people with disabilities through a peer-recruitment approach. In the South Africa stroke

care study, participants were recruited through both community-based organisations and advertising on Facebook.

Recruitment through these organisations and networks carried both limitations and opportunities. On the one hand, DPOs/OPDs, NGOs, and peer networks strengthened the partnerships and trust between the research team and the disability community. For example, in Zambia, Zimbabwe, and other settings, potential participants were cautious about speaking to unfamiliar researchers and were distrustful about how their information would be used; having links with a known organisation helped to reassure them that the study was legitimate and that they could have confidence in the study's data protection measures. Further, organisations were in some cases able to facilitate access to needed technology and accommodations (e.g. sign language interpretation, internet connection) for study participants.

On the other hand, recruitment through organisations carries risks of selection bias. For example, selected participants may be more politically active and connected or have better access to services than is typical for most people with disabilities in the study setting (Young, Reeve and Grills 2016; Grills *et al.* 2020). In the UK, people volunteering to participate through OPDs/DPO recruitment were predominantly white. Further, few older adults with disabilities were identified by NGOs and other organisations in many settings. The extent to which participants linked to organisations were perceived to represent the broader population varied by setting. For example, Bangladesh has a very high concentration of NGOs across the country (Haider 2011); consequently, being linked to an NGO or another organisation in Bangladesh was typical and carried less of a risk of bias. In contrast, in Ghana, the ethics board raised concerns on the representativeness of OPD and NGO recruitment. Consequently, snowball sampling was used to reach additional people not associated with these organisations.

For both forms of recruitment, non-response rates in remote data collection were often higher than in-person data collection pre-pandemic, which has been noted in other Covid-19 studies (Silverwood and Ploubidis 2020). For example, phone numbers on record were frequently disconnected or no longer in use. It was more challenging to address concerns and hesitations when not face to face. Additionally, in many countries, phones belonged to other family members, particularly for women and people with certain types of impairments (e.g. intellectual, psychosocial impairments, Deaf) and people living in poverty. Consequently, the phone owners could act as gatekeepers, preventing access to the person with a disability or influencing their decision to participate. Further, data collection in one Bangladesh study and the Indian study took place during periods of very high Covid-19 incidence. As such, many participants either refused or delayed enrolment because they or other family members were sick for several weeks.

Studies used a range of strategies to reduce non-response and improve access for underrepresented groups. For example, more extended recruitment periods with multiple call-backs were used, and trusted sources assisted recruitment (e.g. OPDs/DPOs, NGOs, peers). Additionally, in Ghana and South Africa, mixed modes of data collection were used, whereby in-person meetings were used for people who were unable or uncomfortable with participating remotely during periods of reduced Covid-19 restrictions. Several studies also have planned rounds of follow-up data collection. Multiple phone numbers and alternative forms of communication less likely to change (e.g. Facebook, email) have been recorded to minimise loss to the follow-up.

### **5.3 Enabling active participation of participants with disabilities**

Capturing the voices of people with disabilities directly is a crucial principle of inclusive research. Therefore, all procedures – from recruitment to consent to data collection – had to be accessible to participants with different types of impairments. New adaptations for remote interviews were needed in addition to standard accessibility procedures used before the pandemic (e.g. documents in easy-to-read, picture formats; availability of sign language interpretation). For example, teams experimented with how to ensure the inclusion of people who are Deaf, given low access to videoconferencing applications and unreliable network/internet connection, such as through text communication over email or messaging applications (e.g. WhatsApp, Facebook, standard texting), or having a household member or in a few cases, a teacher, interpret in person and translate over the phone.

Similarly, a participant in the UK study compiled helpful guidelines for teleconferencing with people with dementia, which included recommendations such as avoiding distracting backgrounds (no bright colours, blurring filters; no or minimal pictures/other objects); encouraging participants to use a pencil/paper to write down their thoughts; keeping questions concise; sending any supporting materials (e.g. PowerPoint files) in advance; and allowing for breaks every 30–45 minutes. Supporting accessibility needs required training of the data collectors, tailoring tools and methods (e.g. simplified information sheets, pictorial representations), and feedback from participants during recruitment on their communication preferences. The involvement of people with disabilities in the research team and advisory groups was essential to identifying and meeting accessibility requirements. The accessibility requirements of staff with disabilities also needed to be implemented (e.g. team video calls with sign language interpretation, closed captioning).

Some studies allowed for the limited use of caregivers, either as a proxy or to support the communication of the person with a disability. For example, caregivers assisted with communication for people with severe communication or intellectual impairments and

people who are Deaf but do not know a standard sign language. Some have developed informal means of communication, particularly in settings where inclusive education and other services are lacking. However, communication through these strategies is often limited and was more difficult over a standard phone call without video or image capabilities. Additionally, proxy caregiver interviews were used instead of direct interviews for people with very severe intellectual or communication impairments who could not participate with existing support.

Teams tried to limit the use of proxy interviews as much as possible by verifying the capabilities of the person with a disability themselves (e.g. asking questions to check for understanding). However, remote data collection made these checks more difficult as there were instances in most projects of the family member who controlled the phone insisting that the person with a disability could not participate (e.g. they would be unable to understand or speak to the research team) and limiting access of the team to the individual to check for themselves. Further, it is important to note that caregivers could have disabilities themselves; in which case, it was essential to provide adaptations for the caregiver's communication and other support needs.

#### **5.4 Ensuring quality standards**

Phone or online calls felt more impersonal and were sometimes disrupted by poor internet/network connection or privacy concerns. These factors can impede rapport- and trust-building, which, when done ethically (Duncombe and Jessop 2002), are vital for qualitative data collection and research on sensitive topics. Therefore, the teams had to develop flexible data collection methods such as multiple shorter calls to build rapport and overcome losses in connectivity or concentration or have some in-person meetings if possible.

Additionally, observations are an essential part of qualitative data collection, allowing the researcher to capture details that can add to or triangulate the participants' verbal responses – such as the dynamics between the participant and other household members, their home and neighbourhood, and the severity of their disability. This type of data was largely lost with remote methods, especially when video calls were impossible, although researchers noted down what they observed or heard during a call. In the South African SRH study, PhotoVoice was integrated into the research methods, enabling participants to provide visual information about their current life experiences. These strategies provided important context information but could not replace direct observation.

Finally, recording and transcribing/translating interviews is often used for qualitative interviews. The quality of recordings was sometimes affected by poor phone/online connections. Detailed notes therefore helped fill in gaps. Ideally, video recordings of sign



language should be reviewed to check that the live interpretation matches what the participant signed. However, this was not possible in many cases due to the limitation in video recording (e.g. when conducted over an audio-only call, where a family member/other person was present with the participant to assist with interpretation). Hence in some studies, debrief reports were used as an alternative to compile data, cut out repetition of questions (because of communication challenges), and using direct quotes and summaries of the conversation.

### **5.5 Adhering to timelines and budgets**

The unpredictable nature of the pandemic had significant implications for project timelines and budgets. The teams experienced disruption due to changing Covid-19 restrictions and infection rates. In South Africa, periods of civil unrest and violence also affected data collection. These challenges could lead to changes in the mode of data collection. For example, the Covid-19 Bangladesh study shifted to remote data collection due to the emergence of the Delta variant. In the WASH studies in Cambodia and Bangladesh, PhotoVoice was originally planned, but could not be implemented due to movement restrictions and safeguarding concerns that limited the ability of the research team to deliver and collect cameras. Similarly, timelines were affected, such as by challenges in recruiting during periods of high infection or unrest. In Cambodia and Bangladesh (WASH study), data collection was delayed by six months because of surges in Covid-19 cases and tighter restrictions, resulting in a project extension.

Remote data collection led to some savings due to reduced travel budgets and new costs for alternatives (e.g. data and/or internet for both participants and home-based researchers). Adequate reimbursement of participants was also essential, given the high costs of data and phone minutes in some settings and the economic challenges faced by many people with disabilities, particularly during the pandemic. There were also changes to how reimbursements were provided, such as bundling payments or using electronic services to avoid having participants frequently travel to ATMs. In-person data collection carried additional costs for PPE (for the research team and participants and their households) and, where available, testing services.

### **5.6 Ensuring the welfare of the research team**

Research under crisis, on sensitive topics, and with particularly marginalised groups increases the strain on a research team. Reports of distress increased due to the pandemic, which was potentially worse for people with disabilities who reported exacerbation of pre-existing exclusion, including severe lack of access to services, food insecurities, and experiences of violence or abuse. Further, researchers themselves were dealing with the consequences of the pandemic through witnessing the illness or death of close relatives, friends, or colleagues, having to work in isolation at home while juggling work, childcare, and other

responsibilities, and in some cases managing their own health and safety after contracting Covid-19 and in times of civil unrest.

Research team members with disabilities may have increased stress during this time, due, for example, to a heightened fear of severe Covid-19 outcomes (ONS 2021), challenges in adapting to Covid-19 protocols and regulations that are non-inclusive (e.g. inaccessible information, lack of support for carrying out preventative measures, disruptions to essential health and social services), and in hearing triggering testimonies from research participants with disabilities.

The need for debriefing and counselling among researchers has been previously highlighted (Jewkes *et al.* 2000; Dickson-Swift *et al.* 2008), as has the importance of ensuring that support is inclusive and appropriate for people with disabilities and other marginalised groups (Kara 2018; Boynton 2020). However, some services (e.g. counselling, in-person debriefs) were disrupted due to the pandemic. Consequently, teams adapted strategies, including creating WhatsApp groups for the research team to share their experiences, challenges, and solutions; providing in-person or remote wellness sessions; mapping mental health services available during restrictions; and having regular online debrief sessions. These strategies had to consider the requirements of research team members with disabilities, both in terms of accessibility (e.g. provision of sign language interpretation, links to accessible services) and scope (e.g. consideration of wellbeing needs that are specific or more prevalent among researchers with disabilities).

#### **6 Ensuring inclusive and effective analysis and dissemination**

Remote working has also led to changes to the analysis process. In-person meetings with the entire research team to discuss findings and develop analysis plans have shifted to online in some instances, as have meetings with DPOs/OPDs and study participants to share emerging findings for feedback, validation, and to co-produce recommendations. Hosting these larger group meetings online has involved continuous learning to ensure that they are productive and support active participation from all attendees.

Some helpful strategies include using breakout rooms for smaller group discussions that are fed back to a larger group; scheduling multiple shorter meetings to keep concentration and engagement; and seeking feedback from participants on what is and is not working with online meetings. Ensuring accessibility throughout is also vital, and accessibility requirements should be sought from participants beforehand so that they are in place for the meeting. Still, hosting group meetings with study participants for validation and feedback was particularly challenging given the lack of access to the required technology in most settings (i.e. internet connection, smartphones for group calls).

Further, teams are critically assessing how some of the challenges in data collection during the Covid-19 pandemic may have affected findings when interpreting study results. For example, remote data collection may lead to high non-response rates and the underrepresentation of certain groups (e.g. people living in poverty, people with certain impairments). Teams will have to consider the extent to which these risks were mitigated and the impact on the quality and validity of results.

Given the restrictions on large gatherings, many disseminating events were replaced by online events during the pandemic. The move to online modes of dissemination has improved access for people with disabilities who have reliable internet connections and would have challenges attending face-to-face events (e.g. physically or financially inaccessible spaces or transportation, the need for someone to accompany). Nevertheless, webinars and online meetings must be accessible (e.g. sign language interpretation where the interpreter is pinned for the duration of the webinar, closed captioning).

Further, many people, particularly people with disabilities and in low- and middle-income countries, lack access to reliable internet and technologies. Therefore, communicating results back to study participants and widespread dissemination within the disability community has required mixed strategies, such as leaflets with pictograms, text/WhatsApp notifications, and linkages to websites or YouTube recordings. Engagement with OPDs and NGOs is also essential to reach people with disabilities. As restrictions ease, teams are planning for mixed modes of dissemination, including in-person events with live recording to build off the advantages and reduce the disadvantages of each strategy.

Research teams also had to consider safety and confidentiality when using online dissemination formats. Dissemination events ideally provide a space for study participants or their representatives to speak for themselves. However, online events are accessible to many people. This broader participation can be of concern for sensitive topics such as gender-based violence or sexuality. Research teams, therefore, had to develop approaches on how to enable this representation safely. These approaches included a careful analysis of risks and benefits and discussion of these with participants.

In many cases, mainly where recordings were used, participants had to provide additional consent. For sensitive topics, some teams also choose to pre-record part of an online session and review and approve the footage with the participants before it goes online. Other approaches include presenting without video, statements read out by another person, and closed events without online publication.

## 7 Conclusion

This article provides an overview of key challenges, opportunities, and potential mitigation strategies implemented by several research teams during the Covid-19 pandemic. While its focus is on adaptations to disability research methods and practices made due to the pandemic, these strategies will likely be relevant going forward. For example, remote communication is still common even as some countries are removing Covid-19 restrictions. With increasing technological advances and connectedness, people with disabilities must not be left behind.

Additionally, the challenges and strategies outlined could apply to future outbreaks or emergencies where similar restrictions may be in place (e.g. natural disasters, humanitarian contexts). Further, some of the innovations from research during the pandemic, such as the use of mixed modes of data collection and dissemination to reach different groups, can be used to overcome barriers to inclusion in research that were present before the pandemic. Although this study drew from lessons learned from disability-focused studies, other studies that are not necessarily disability focused should still consider the challenges and adaptations discussed – in addition to guidelines for other groups at risk of exclusion (Nind *et al.* 2021) – to ensure that their research does not exclude the experiences of people with disabilities.

## Notes

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