

# BMJ Open Did high frequency phone surveys during the COVID-19 pandemic include disability questions? An assessment of COVID-19 surveys from March 2020 to December 2022

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**To cite:** Nascimento Dial A, Vicente D, Mitra S, *et al*. Did high frequency phone surveys during the COVID-19 pandemic include disability questions? An assessment of COVID-19 surveys from March 2020 to December 2022. *BMJ Open* 2024;**14**:e079760. doi:10.1136/bmjopen-2023-079760

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2023-079760>).

Received 11 September 2023  
Accepted 19 June 2024



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## ABSTRACT

**Objectives** In the midst of the pandemic, face-to-face data collection for national censuses and surveys was suspended due to limitations on mobility and social distancing, limiting the collection of already scarce disability data. Responses to these constraints were met with a surge of high-frequency phone surveys (HFPSs) that aimed to provide timely data for understanding the socioeconomic impacts of and responses to the pandemic. This paper provides an assessment of HFPS datasets and their inclusion of disability questions to evaluate the visibility of persons with disabilities during the COVID-19 pandemic.

**Design** We collected HFPS questionnaires conducted globally from the onset of the pandemic emergency in March 2020 until December 2022 from various online survey repositories. Each HFPS questionnaire was searched using a set of keywords for inclusion of different types of disability questions. Results were recorded in an Excel review log, which was manually reviewed by two researchers.

**Methods** The review of HFPS datasets involved two stages: (1) a main review of 294 HFPS dataset-waves and (2) a semiautomated review of the same dataset-waves using a search engine-powered questionnaire review tool developed by our team. The results from the main review were compared with those of a sensitivity analysis using and testing the tool as an alternative to manual search.

**Results** Roughly half of HFPS datasets reviewed and 60% of the countries included in this study had some type of question on disability. While disability questions were not widely absent from HFPS datasets, only 3% of HFPS datasets included functional difficulty questions that meet international standards. The search engine-powered questionnaire review tool proved to be able to streamline the search process for future research on inclusive data.

**Conclusions** The dearth of functional difficulty questions and the Washington-Group Short Set in particular in HFPS has contributed to the relative invisibility of persons with disabilities during the pandemic emergency, the lingering effects of which could impede policy-making, monitoring and advocacy on behalf of persons with disabilities.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We reviewed 293 high-frequency phone survey (HFPS) questionnaires from 72 countries across all World Bank regions, providing a comprehensive and timely account of the visibility of persons with disabilities in national data collection efforts during the COVID-19 pandemic.
- ⇒ Some HFPS datasets were not covered in this study because their questionnaires were not yet available or not available in a language the authors understood.
- ⇒ The list of keywords used to search HFPS questionnaires is not exhaustive and might not have included terms used to refer to disability that seem outdated but that may still be used in some surveys.
- ⇒ We did not evaluate the implementation of surveys in the field, and therefore, have no information regarding how or whether disability questions may have been asked in practice.

## INTRODUCTION

Data inform individuals, benefit communities and can be used to reduce inequalities.<sup>1</sup> Global efforts to improve the quality, quantity, availability and financing of disaggregated data portrayed in the Inclusive Data Charter are crucial to attaining the 2030 United Nations (UN) Sustainable Development Goals (SDGs). Since the adoption of the UN SDGs, there has been a growing focus on the inclusion of traditionally marginalised and disadvantaged groups.<sup>1</sup> Disaggregated data shall enable us to ensure that ‘no person—regardless of ethnicity, gender, geography, disability, race or other status—is denied universal human rights’.<sup>1–3</sup>

Human rights frameworks such as the Convention on the Rights of Persons with Disabilities (CRPD) reinforce the inclusive nature of the UN SDGs. Article 31 of the

CRPD requires its signatory states to collect statistical and research data to enable them to formulate and implement policies to give effect to their mandate.<sup>4</sup>

### The COVID-19 pandemic and data collection

Less than a decade away from the 2030 deadline to reach the UN SDGs, the COVID-19 may have undermined progress made regarding the inclusion of persons with disabilities.<sup>5</sup> Emerging literature shows that COVID-19 disproportionately affected persons with disabilities worldwide, exacerbating prior existing social inequities.<sup>1-3</sup> Mortality from COVID-19 was significantly higher in the population with developmental disabilities than in the general population.<sup>6 7</sup> Persons with disabilities endured higher rates of depression, anxiety and stress.<sup>8</sup> Furthermore, due to the pandemic, persons with disabilities experienced higher exclusion from social protection mechanisms and poverty than non-disabled peers.<sup>9</sup>

These few studies on the disproportionate negative effects of the pandemic on persons with disabilities suggest that there may be much larger social effects that remain invisible due to a lack of disability disaggregated data. Surveillance mechanisms established by domestic governments and inter-regional organisations did not systematically collect comparable, high-quality disability data. Such exclusion has widened the gap of already scarce high-quality disability data.<sup>1</sup>

Public health surveillance for persons with disabilities has been limited before, during and after COVID-19.<sup>10</sup> During COVID-19, emergency measures such as lockdowns led to delays in data collection such as national censuses and surveys. International efforts to standardise measurements of disability and functional difficulties were challenged by the rush to implement a COVID-focused surveillance mechanism.<sup>11</sup> As time progressed, we saw that data on COVID-19 cases and deaths tended to report on age, sex and ethnicity or race but not on disability status despite the early call of organisations of persons with disabilities (OPDs) for disability-inclusive pandemic responses and data collection.<sup>12 13</sup> However, unlike age, gender and ethnicity or race, data on disability status and functional difficulties are neither compulsory nor common practice to collect.<sup>13</sup>

### Promoting inclusive data collection: the Washington Group Short Set

For over two decades, the UN Washington Group on Disability Statistics has worked towards standardising disability measures suitable for national censuses and surveys. This group of international experts has proposed the Washington Group Short Set of questions (WG-SS) focusing on six core functional domains: seeing, hearing, walking, cognition, self-care and communication. The WG-SS uses a four-level answer scale (no difficulty, some difficulty, a lot of difficulty or cannot do at all). The WG-SS does not use the term disability as it may be understood differently across cultures and could be stigmatised in some contexts.<sup>14</sup> Online supplemental appendix table

1 includes the WG-SS questions as they are commonly used in surveys.

The WG-SS has been extensively tested and validated in all regions of the world and has been used globally to effectively measure the prevalence of disability.<sup>15</sup> As WG-SS implementation progresses, so does the methodological understanding of its use and reach.<sup>16</sup> Evidence shows that the WG-SS can unveil inter-regional differences, overcoming the limitation of traditional national averages that tend to hide important local variations. The WG-SS allows a fine level of disaggregation by functional difficulty and severity, enabling one to compare and see who has been left behind.<sup>16 17</sup> Data that emerge from the WG-SS are internationally comparable and could be used to leverage changes domestically and internationally.

### Collecting data on functional difficulties and disability: COVID-19 high frequency phone surveys

In the midst of the pandemic, face-to-face data collection was suspended due to limitations on mobility and social distancing. These constraints were met by a surge of phone surveys that aimed to provide timely data for understanding the socioeconomic impacts of and responses to the pandemic. COVID-19 high-frequency phone surveys (HFPSs) of households typically involve 10–15 min phone calls; sampling methods varied across regions and so did the number of waves of data collection from 2 to 8.<sup>18</sup> HFPSs use computer-assisted telephone interviews techniques for design and implementation.

Inter-regional organisations, including the World Bank, European Commission and US Agency for International Development (USAID), collected data worldwide via HFPS, looking at the pandemic's socioeconomic impacts. The surveys were linked to ongoing household surveys and zoomed into various indicators of coping strategies, including employment loss and income, health and well-being, food security and education.<sup>18 19</sup>

HFPSs were frequently initiated as part of broader international efforts on behalf of the World Bank and UN Women.<sup>20 21</sup> International programmes have been implemented in all regions. The World Bank has carried out COVID-19 HFPS in 89 countries, concentrating in Europe and Central Asia, East Asia and the Pacific, Latin America and the Caribbean and sub-Saharan Africa.<sup>20</sup> UN Women employed Rapid Gender Assessments across 58 countries in East Asia and the Pacific, Europe and Central Asia, Latin America and the Caribbean, the Middle East and North Africa (MENA) and sub-Saharan Africa.<sup>21</sup>

Although many national governments collaborated with international organisations such as the World Bank and UN Women in the design and implementation of HFPS, rarely did they conduct their surveys independently.<sup>19 20</sup> Only two countries whose surveys were covered in this study employed HFPS programmes that originated at the national level: Sri Lanka through the Department of Census and Statistics and the USA through the Census Bureau. The MENA was the only region to have an HFPS programme that originated at the regional level

**Table 1** Description of HFPS under review

Region	Types of Programmes initiated	Main supporting Organisations	Year(s) Covered	Survey languages	Number of countries	Number of datasets
East Asia and the Pacific	International Joint	National Governments UNICEF World Bank	2020–2021	English	8	8
Europe and Central Asia	International Joint	National Governments NGOs UNICEF UN Women USAID World Bank	2020–2021	English	10	13
Latin America and the Caribbean	International Joint	National Governments UNDP World Bank	2020–2021	English Spanish Portuguese	22	23
Middle East and North Africa	International Regional	Economic Research Forum UNHCR World Bank	2020–2021	English	4	5
North America	International National	National Governments UN Women UNDP World Bank	2020–2022	English Spanish	2	3
South Asia	International Independent National	National Governments NGOs World Bank	2020	English	2	2
Sub-Saharan Africa	International Joint	National Governments UNICEF UN Women World Bank	2020–2022	English French	24	39

\*Joint refers to programmes where international or regional organisations consulted and involved national governments and/or NGOs in survey designs, implementation, etc.

†Independent refers to initiatives undertaken by independent organisations like universities, NGOs or research companies.

HFPS, high-frequency phone survey; NGO, non-governmental organisation; UNDP, United Nations Development Programme; UNHCR, United Nations High Commissioner for Refugees; USAID, United States Agency for International Development.

to facilitate cross-country comparable research between Arab countries: the COVID-19 MENA Monitor Survey conducted by the Economic Research Forum (ERF).<sup>22</sup>

This paper provides an assessment of HFPS datasets and their inclusion of disability questions to evaluate the visibility of persons with disabilities during the COVID-19 pandemic. To support the analyses of the datasets, we use an information retrieval model implementing the WG-SS query templates in a semiautomated way. Further, the discussion identifies strategies for the rapid evaluation of data collection tools that shall help researchers in disability-focused research and beyond and future research on the design, assessment and implementation of phone surveys and other data collection tools.

## METHODS

### Online search for HFPS

We searched for HFPS conducted globally from the onset of the pandemic emergency in March 2020 until December 2022.

HFPS datasets and their questionnaires were retrieved from the World Bank Microdata Library, the UN Women Rapid Gender Assessment data repository, the ERF Microdata catalogue, the UNICEF website and the websites of individual National Statistical Offices. [Table 1](#) gives a description of the HFPS included in this study. HFPS datasets were found in all seven world regions with a majority from sub-Saharan Africa and Latin America and the Caribbean between March 2020

and December 2021. In 2022, HFPS questionnaires were only found for countries in North America and sub-Saharan Africa.

There were no systematic applications of the HFPS, nor were they publicly documented or made available as microdata. Due to variations in how these data are reported, we searched manually for HFPS questionnaires across different online repositories. Some inter-regional organisations, such as those listed above, supported and made available HFPS. Furthermore, we relied on the Disability Data Initiative's annual reviews of available disability disaggregated datasets. These reviews cover North America, Latin America and the Caribbean, sub-Saharan Africa, Europe and Central Asia, East Asia and the Pacific, and guide the identification of available datasets used in this paper. Nonetheless, as discussed in more detail below, these resources face limitations due to inconsistent language or lack of systematic documentation of the instruments utilised. As such, our review may not be exhaustive.

The language of HFPS questionnaires available from online repositories varied. HFPS datasets were primarily available and reviewed in English, but some were available and reviewed in one of the three additional languages understood by the authors: French, Portuguese and Spanish. The majority of questionnaires were reviewed in English, followed by Spanish, French and Portuguese. [Table 1](#) also provides a breakdown of the languages of surveys reviewed in each region.



Some datasets were rolled out over multiple rounds. The term dataset-wave refers to an individual round of data collection for such datasets. Dataset-waves may be part of a longitudinal dataset or repeated cross-sections.

The resulting pool of HFPS datasets included 93 datasets and 294 dataset-waves from 72 countries in East Asia and the Pacific (8 countries), Europe and Central Asia (10 countries), Latin America and the Caribbean (22 countries), the MENA (4 countries), North America (2 countries), sub-Saharan Africa (24 countries) and South Asia (2 countries). The full list of datasets that were reviewed, along with their respective languages, is available in online supplemental appendix table 2.

### Questionnaire review of HFPS

Each of the 294 dataset-waves was searched for disability questions that are commonly used in surveys and censuses: functional difficulty questions that meet international standards (WG-SS or other functional difficulty), broad activity limitation, activities of daily living (ADLs), general disability and other disability-related questions.

The different types of disability questions above were found using a set of disability-related keywords noted in the following italics: *difficulty in seeing, hearing, walking, concentrating, remembering, self-care (bathing, dressing), communication, limited in usual activit(y)ies, limited in the amount of work/school or type of work/school or activities related to work/school, ADLs (eating, toileting, urination, defecation, housework, shopping, cooking, managing money, taking medicine), disability, impairment (blind, deaf, mental, physical), benefits (pension, grant, cash), discrimination.*

Below, we briefly describe the different types of disability questions.

### Types of disability questions

Functional difficulty questions are used to determine an individual's degree of difficulty in performing certain bodily functions and must cover at least the four functional domains recommended by the UN Statistical Commission: (a) walking, (b) seeing, (c); hearing and (d) cognition.<sup>23</sup> Such questions may include two additional domains: self-care and communication. Functional difficulty questions include but are not limited to the WG-SS. We consider questions that are similar to the WG-SS and meet the UN (2017) guidelines but vary with respect to the wording of questions, answer scale and domains included as 'other functional difficulty questions'.<sup>24</sup>

Surveys may have other disability-related questions that do not meet the UN (2017) guidelines. Some surveys, especially beginning during the pandemic emergency, use the single functional difficulty question. Single functional difficulty questions are similar to functional difficulty questions in that they are used to capture difficulties across the six functional domains but differ significantly in their structure. They use only one question asked at the household level to determine whether members of the household present difficulties in any of the six domains such as: Do you/Does anyone in your household

have difficulty in seeing, hearing, walking, remembering, self-care or communication? However, since responses use a yes/no answer scale, respondents are unable to distinguish between which difficulties they experience and to what degree. In some cases, single functional difficulty questions might ask Do you have difficulty in any of the following? and respondents give a single answer by selecting one of the six domains. This type of answer choice ignores the possibility that respondents may experience difficulties in multiple domains each in varying degrees. Thus, single functional difficulty questions are insufficient to adequately capture functional difficulties and are not considered functional difficulty questions that meet the UN (2017) guidelines.

A broad activity limitation question asks the respondent if they are limited in their usual activities such as attending work or school due to an impairment or health condition.<sup>24</sup> It is used to capture an individual's capacity to undertake tasks and social responsibilities typical of persons in a similar age group. Similar to broad activity limitation questions, activities of daily living questions (ADLs) ask the respondent if they experience difficulties in basic daily activities such as walking a certain distance or performing self-care without help. ADLs may also include intermediate tasks such as shopping or housekeeping. Broad activity limitation and ADL questions are limited in their cross-country comparability as conceptions of 'usual activities' and 'daily activities' may vary considerably in an international context.

General disability questions ask respondents about their disability status in general and are usually of the form: Do you have a disability? They are sometimes followed by additional questions about the type of disability or impairments that the respondent experiences. While general disability questions capture an individual's disability identity, their inadequacy as a measure of disability is problematic. Perceptions and definitions of disability vary across individuals and contexts and some individuals with less severe impairments may not consider themselves as persons with disabilities.<sup>24</sup>

Additional disability-related questions do not fall into any of the above categories. These include disability benefit questions about services or benefits (such as pensions, grants or cash assistance) respondents receive due to their disability status. Discrimination questions ask respondents if they have experienced less favourable or exclusionary treatment, harassment or other forms of discrimination because of a disability.

### Questionnaire review approaches

The review of HFPS datasets involved two stages: (1) a main review of each of the 294 dataset-waves and (2) a semiautomated review of the same dataset-waves using a search engine-powered tool developed by our team. The results from the main review were used to perform a sensitivity analysis on the semiautomated results to test the strength of the tool as a viable alternative to manual search, which is labour-intensive and time-consuming.

The search tool has the potential to streamline the search process for future research on inclusive data.

### Main review

Each questionnaire was reviewed manually by two researchers. One researcher used the keywords above to search for the different types of disability questions and recorded results in an Excel review log. The second researcher reviewed each questionnaire in a similar manner and performed a comprehensive check of the results in the review log. The main review was conducted from November 2022 to January 2023.

### Sensitivity analysis

Following the main review, each questionnaire was uploaded to a questionnaire review tool (S4) developed to automate the manual search process. The questionnaire review tool is available at <https://heg-r1001.hesge.ch/ddi/analyze>. The tool uses the term-frequency inverse document frequency (TF-IDF) framework to compute the similarity between a query, that is, the set of keywords, and a document, that is, the HFPS. The more a keyword is found in a document, the more it is relevant to the document. Conversely, the less a keyword is found in the HFPS, the less relevant it is for the search.<sup>25</sup> The code for the questionnaire review tool is available at [https://github.com/davidvicentealvarez/DS4DH-DDI-search\\_tool](https://github.com/davidvicentealvarez/DS4DH-DDI-search_tool).

The same keywords used in the manual search were added to the search tool as query templates. Questionnaires were then uploaded to the tool and were indexed

using Elasticsearch. During the search phase, the tool automatically computes the similarity between the input query and the indexed documents using the TF-IDF framework,<sup>26–28</sup> more specifically the BM25 model, which also considers document length and term saturation. Then, the tool provides as results for a query a ranked list of questionnaires matching the search template. Additionally, to improve usability, for a selected questionnaire in the list, it detects all disability-relevant blocks of text and records the search results in a review log.

### Patient and public involvement

None.

## RESULTS

### Main review

Table 2 gives the shares of countries and surveys with or without the various types of disability questions found in HFPS: WG-SS, other functional difficulty, single functional difficulty, broad activity limitation, general disability, disability benefit and discrimination questions.

In total, 46 HFPS datasets (87 dataset-waves) across 43 countries included any disability question between 2020 and 2022. However, during the height of the COVID-19 emergency, HFPS datasets tended to exclude questions on functional difficulties that meet international standards, especially the internationally comparable WG-SS. Of the 93 datasets covered, only 2 datasets were found to

**Table 2** Results overview

	Countries		Datasets		Dataset-waves	
	Number	Percentage	Number	Percentage	Number	Percentage
All reviewed	72	100.0	92	100.0	293	100.0
With any disability question	<b>43</b>	<b>59.7</b>	<b>46</b>	<b>50.0</b>	<b>87</b>	<b>29.7</b>
With functional difficulty questions	<b>2</b>	<b>2.8</b>	<b>3</b>	<b>3.3</b>	<b>8</b>	<b>2.7</b>
WG-SS	2	2.8	2	2.2	4	1.4
Other functional difficulty questions	1	1.4	1	1.1	4	1.4
With other disability questions	<b>42</b>	<b>58.3</b>	<b>46</b>	<b>50.0</b>	<b>82</b>	<b>28.0</b>
Single functional difficulty	32	44.4	32	34.8	55	18.8
Broad activity limitation	1	1.4	1	1.1	1	0.3
General disability	7	9.7	7	7.6	7	2.4
Disability benefit	6	8.3	8	8.7	21	7.2
Discrimination	8	11.1	8	8.7	8	2.7

Bold values signify any disability question.

\*Source: Authors' own calculations based on HFPS dataset review.

†Any disability question refers to surveys that were found to have any disability questions that fall under the following categories: functional difficulty or other disability questions.

‡Functional difficulty questions could be the WG-SS or other functional difficulty questions. The number of countries with functional difficulty questions is not the sum of the numbers of countries with the WG-SS and with other functional difficulty questions as some countries have both.

§The number with any disability question does not add to the total number reviewed because not all countries, datasets and dataset-waves reviewed had disability questions.

HFPS, high-frequency phone survey; WG-SS, Washington Group Short Set.

**Table 3** Results overview by language

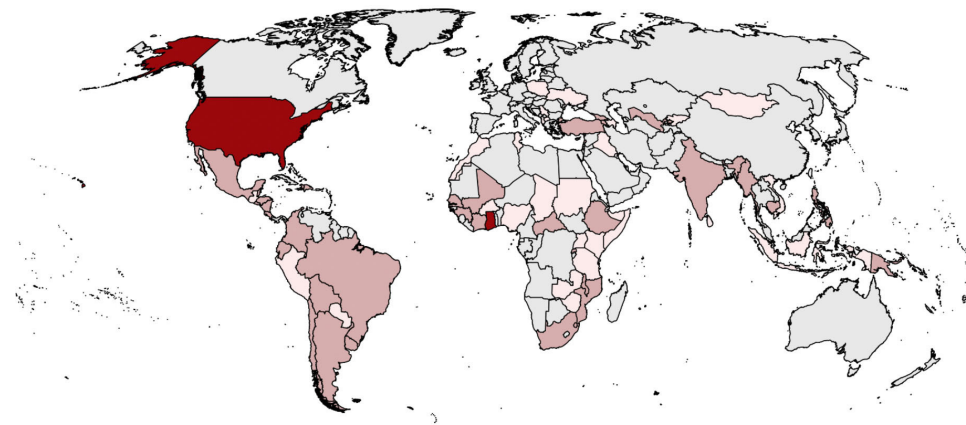
	Countries					Dataset-waves					Total	Percentage
	English	Spanish	French	Portuguese	English	Spanish	French	Portuguese	English	Spanish		
Reviewed	63	13	7	1	234	44	13	2	293	100.0		
With any disability question	<b>37</b>	<b>1</b>	<b>5</b>	<b>1</b>	<b>79</b>	<b>1</b>	<b>5</b>	<b>2</b>	<b>87</b>	<b>29.7</b>		
With functional difficulty questions	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>8</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>8</b>	<b>2.7</b>		
WG-SS	2	0	0	0	4	0	0	0	4	1.4		
Other functional difficulty questions	1	0	0	0	4	0	0	0	4	1.4		
With other disability questions	<b>36</b>	<b>1</b>	<b>5</b>	<b>1</b>	<b>74</b>	<b>1</b>	<b>5</b>	<b>2</b>	<b>82</b>	<b>28.0</b>		
Single functional difficulty	27	0	5	1	50	0	4	1	55	18.8		
Broad activity limitation	1	0	0	0	1	0	0	0	1	0.3		
General disability	6	1	0	0	6	1	0	0	7	2.4		
Disability benefit	6	0	0	0	21	0	0	0	21	7.2		
Discrimination	3	0	5	0	3	0	5	0	8	2.7		

Bold values signify surveys found with any disability question.

\*Source: Authors' own calculations based on HFPS dataset review.

†The number of countries reviewed is not the sum as reported in [table 2](#) because some countries had surveys with questionnaires in multiple languages.

‡The total and percentage columns under dataset-waves refer to the total number of dataset-waves reviewed and their respective percentages in each category. These numbers correspond exactly with the final two columns of [table 2](#).  
HFPS, high-frequency phone survey; WG-SS, Washington Group Short Set.



**Figure 1** Countries identified with functional difficulty questions, other disability questions or no disability-related questions.

use the WG-SS: Ghana's COVID-19 Households and Jobs Survey and the US Household Pulse Survey. In Ghana, the WG-SS was employed early into the pandemic emergency during the first wave of the 2020 COVID-19 Households and Jobs survey and its use was continued into the survey's third wave. Take-up of the WG-SS was later in the USA: it first incorporated other functional difficulty questions in 2021 during the seventh wave of the Household Pulse Survey. In 2022, as part of the eleventh wave, it adopted the WG-SS.

**Table 3** reports the share of dataset-waves with or without disability questions by language. The majority of dataset-waves reviewed were in English, a total of 234 dataset-waves, followed by Spanish (44 dataset-waves), French (13 dataset-waves) and Portuguese (2 dataset-waves). English language surveys were available in all regions, with French language surveys available for seven countries in sub-Saharan Africa and Spanish language surveys in 13 countries in Latin America and the Caribbean and one in North America (countries with French language surveys include Central African Republic, Chad, Côte d'Ivoire, Djibouti, Guinea, Mali and Senegal. Countries with Spanish language surveys include Argentina, Bolivia, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Paraguay, Peru and Mexico. Countries with Portuguese language surveys include Brazil. English language surveys accounted for over 90% of the surveys found with any disability question and were the only surveys to have functional difficulty questions. Online supplemental appendix table 3 provides the yield of datasets by language and by country.

**Figure 1** maps countries that used functional difficulty questions (either the WG-SS or other functional difficulty), other disability questions or no disability-related questions. North America and sub-Saharan Africa were the only two regions for which HFPS datasets used functional difficulty questions that meet international standards. Even so, the WG-SS was not used widely in these two regions. Only 2 of the 72 countries for which HFPS datasets were reviewed had functional difficulty questions: Ghana and the USA.

Overall, 59.7% of countries had at least a question on disability. Among countries with any disability-related questions, the single functional difficulty question was the most frequently used: 44.4% of all countries reviewed, and 74.4% of countries that used any disability question, used the single functional difficulty question.

**Table 4** gives the share of datasets with or without the various types of disability questions found in HFPS datasets by region. As shown in **table 4**, North America had the highest usage of any disability question in HFPS datasets followed by Latin America and the Caribbean; the MENA had the lowest usage.

Across regions, usage of the single functional difficulty question is highest in Latin America and the Caribbean and sub-Saharan Africa at 87% and 28.2% of HFPS datasets, respectively. The single functional difficulty question is the most frequent choice of disability question when HFPS datasets use any disability question in Latin America and the Caribbean and sub-Saharan Africa: 95.2% and 78.6% of HFPS datasets in these regions, respectively, with any disability question use a single functional difficulty question. In sub-Saharan Africa, the single functional difficulty question was used in some HFPS datasets in 2020 when the pandemic emergency began. However, in Latin America and the Caribbean, it was notably excluded from HFPS datasets in 2020. The single functional difficulty question appeared later in Latin America and the Caribbean during the first couple of HFPS waves in 2021.

In North America, Mexico was the only country to use the single functional difficulty question. Europe and Central Asia, East Asia and the Pacific, the MENA and South Asia used neither functional difficulty questions nor the single functional difficulty question.

Other disability-related questions found in COVID-19 surveys included broad activity limitation, general disability, disability benefit or discrimination questions. Mexico was the only country to use a broad activity limitation question. Europe and Central Asia, East Asia and the Pacific, the MENA and South Asia used only general disability questions or disability benefit questions. Discrimination questions were only found in HFPS datasets in sub-Saharan Africa. A full list of HFPS datasets with

**Table 4** Overview of regional results

	Global	Latin America and the Caribbean				Middle East and North Africa	Sub-Saharan Africa	South Asia
		Europe and Central Asia	East Asia and the Pacific	Caribbean	North America			
Datasets reviewed	93	13	8	23	3	5	39	2
With any disability question (%)	<b>49.5</b>	<b>38.5</b>	<b>25.0</b>	<b>91.3</b>	<b>100.0</b>	<b>20.0</b>	<b>35.9</b>	<b>50.0</b>
With functional difficulty questions (%)	<b>3.2</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>33.3</b>	<b>0.0</b>	<b>2.6</b>	<b>0.0</b>
WG-SS (%)	2.2	0.0	0.0	0.0	33.3	0.0	2.6	0.0
Other functional difficulty (%)	1.1	0.0	0.0	0.0	33.3	0.0	0.0	0.0
With other disability questions (%)	<b>49.5</b>	<b>38.5</b>	<b>25.0</b>	<b>91.3</b>	<b>100.0</b>	<b>20.0</b>	<b>33.3</b>	<b>50.0</b>
Single functional difficulty (%)	34.4	0.0	0.0	87.0	33.3	0.0	28.2	0.0
Broad activity limitation (%)	1.1	0.0	0.0	0.0	33.3	0.0	0.0	0.0
General disability (%)	7.5	15.4	12.5	4.3	33.3	20.0	0.0	50.0
Disability benefit (%)	8.6	23.1	12.5	0.0	33.3	0.0	7.7	0.0
Discrimination (%)	8.6	0.0	0.0	0.0	0.0	0.0	20.5	0.0

Bold values signify highest usage of any disability question in HFPS.

\*Source: Authors' own calculations based on HFPS dataset review.

HFPS, high-frequency phone survey; WG-SS, Washington Group Short Set.



disability-related questions is available in online supplemental appendix table 4.

In some countries, disability questions were not used consistently across waves in the same datasets. Occasionally, disability questions appear in one wave and disappear in the next or change type over time. One such notable case is Cambodia's 2020 COVID-19 HFPS of Households. Initially, the survey used a general disability question in its first wave but dropped it in its subsequent four waves. However, such cases seem to be anomalies; there is a relative tendency for HFPS datasets to adopt disability questions if initially they excluded them or preserve them if they included them. However, for datasets with multiple waves, we do not find a tendency for datasets to adopt the WG-SS or other functional difficulty over time between 2020 and 2022; the US Household Pulse Survey is a singular case of such an occurrence.

### Sensitivity analysis

Online supplemental tables 5 and 6 give the shares of countries and HFPS with or without the various disability-related questions found using the semiautomated review, along with the shares by region, respectively. In total, 45 countries and 49 datasets (89 dataset-waves) were found with any disability question. Thus, the results from the semiautomated review are consistent with the results from the manual review.

When results differed from the manual review, the search tool tended either to find slightly more disability questions or to improve the characterisation of disability questions found in the manual review. An additional dataset was found with other functional difficulty questions: Gambia's 2020 COVID-19 HFPS. The search tool most frequently identified additional disability benefit questions, but also a discrimination and general disability question. The search tool did not find a broad activity limitation question.

## DISCUSSION

We conducted a review of 93 COVID-19 HFPS datasets (294 dataset-waves) across 72 countries to determine the extent to which they included disability-related questions during the pandemic emergency. We outline our main results below.

### Main results

First, COVID-19 HFPS did not altogether exclude disability-related questions. Almost half of HFPS datasets reviewed and 60% of countries under study had some type of question on disability. The most commonly used question is the single functional difficulty question, which does not adequately capture functional difficulties: it was used in 32 countries primarily in Latin America and the Caribbean and sub-Saharan Africa. Other disability-related questions found in HFPS included broad activity limitation, general disability, disability benefit and discrimination questions.

Second, while disability questions were not widely absent from COVID-19 surveys, usage of functional difficulty questions that meet international standards is low globally. Only two countries used functional difficulty questions as per the UN (2017) guidelines: Ghana and the USA. Less than 3.5% of HFPS datasets used any functional difficulty questions and only 2.2% used the internationally comparable WG-SS.

Third, HFPS datasets with multiple waves that use disability-related questions tend to use them consistently across waves. However, there is a lack of wide-scale uptake of the WG-SS, or functional difficulty questions in general, in COVID-19 HFPS over time throughout the pandemic emergency. This is contrary to recent global trends in the inclusion of the WG-SS in surveys and censuses, which suggest that its usage has increased throughout the 2010s.<sup>10</sup> This finding is surprising as many of the organisations that supported HFPS programmes have signed the Inclusive Data Charter.<sup>29</sup>

### Limitations and suggestions for further research

This analysis is not without limitations. First, the HFPS datasets under consideration in this study account for efforts implemented in 72 countries, mostly in low-income and middle-income countries, and, therefore, our results may not be representative at the global level and within regions. Some HFPS datasets were not covered either because their questionnaires were not yet available or not available in a language that the authors understood: English, French, Portuguese or Spanish. We neither have information on the quality of available translations for datasets into languages the authors can read; incorrect or lacking translations make it difficult to accurately determine whether such datasets include disability questions (and of what type). It is also possible that some available HFPS questionnaires may have been missed. Subsequent analyses have potential to reveal further, more representative insights from a greater sample of HFPS datasets as they become more readily available.

Second, the list of search terms used is not exhaustive and may not have included terms used to refer to disability that seems outdated (such as handicap) but that may continue to be used in some surveys.

Finally, as we focused on reviewing questionnaires, we did not evaluate how HFPS were implemented in the field. While we may have found relevant disability questions in a questionnaire, we have no information regarding how or whether they were asked in practice. Likewise, phone surveys pose significant accessibility limitations for persons with disabilities, especially persons with communication or hearing difficulties, who may have difficulties responding over the phone.<sup>30</sup> We did not evaluate interviewer sensitivity training on asking disability-related questions to respondents.

Despite these limitations, the results of this study provide important insights into the nature of persons with disabilities' inclusivity and visibility in surveys implemented during the pandemic emergency.

Further research is needed to address the limitations of this study and to consider related disability data issues, such as the allocation of resources towards, and the implementation of, relevant training in surveys that do have functional difficulty questions. Research is also necessary to exploit HFPS data on disability when available (eg, in Mexico and the USA), to illustrate the importance of such data and the insights they can lead.<sup>31</sup>

## Conclusions

The disruption of data collection efforts during the pandemic may hinder the timely achievement of the 2030 Agenda for Sustainable Development, which stipulates the need to monitor progress through greater availability of high-quality disaggregated data.<sup>32</sup> In times of crisis, HFPSs have the potential to meet unfulfilled needs spurred by pauses in face-to-face data collection to maintain the availability of data.<sup>33</sup> Mobile phones show promise as a means of collecting high-quality data for high-frequency surveys, and with mobile phone usage on the rise in low-income and middle-income countries, HFPS may become a mainstay of national and global data collection efforts.<sup>33 34</sup> Yet, there is a need for guidelines for inclusive practices and accessibility for phone surveys to ensure that barriers do not prevent persons with hearing or communication difficulties from responding in meaningful ways.<sup>30</sup>

Inclusive and disaggregated data are essential to ensuring that no one is left behind.<sup>29</sup> During COVID-19, HFPS longitudinal data provided critical opportunities to capture the effects of the pandemic on persons with disabilities and on the incidence of functional difficulties. The frequent usage of other disability-related questions, particularly the single functional difficulty question, suggests that HFPS programmes might have been well intentioned with respect to their inclusion of disability in data collection efforts. However, the dearth of functional difficulty questions, and the WG-SS in particular, in HFPS has contributed to the relative invisibility of persons with disabilities during the pandemic emergency.

As national statistics offices and organisations (UNHCR, UNICEF, UN Women, USAID and the World Bank) continue to implement HFPS and other surveys that monitor the situation of populations now in a postpandemic context, they should make systematic commitments to support and prioritise the inclusion of internationally comparable functional difficulty questions such as the WG-SS in survey questionnaires that may make up for gaps in the available data on disability during COVID-19. Such commitments are instrumental in producing high-quality data on the situation of persons with disabilities, ensuring that they are not left behind.

**Contributors** AND: data curation and analysis, original draft preparation, editing, visualisation. DV: tool development, editing. SM: conceptualisation, editing, methodology, funding acquisition, supervision. DT: conceptualisation, editing, supervision. MRV: conceptualisation, editing, funding acquisition, supervision and guarantor.

**Funding** We acknowledge funding from the Wellspring Philanthropic Fund. The last author (MRV) was supported by the Swiss National Science Foundation under the award Ambizione (186035).

**Disclaimer** The funders had no role in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation, review or approval of the manuscript; and decision to submit the manuscript for publication.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request.

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