

Evidence summary: Disability data and eye health programming in low- to middle-income countries

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Abbreviations

Acronym	Description
CFM	WG/UNICEF Child Functioning Module
CRPD	UN Convention on the Rights of Persons with Disabilities
CSC	Cataract surgical coverage
DDD	Disability-disaggregated data
HMIS	Health management information system
IAG	Inclusion Advisory Group, CBM Global
LMIC	Low- to middle-income country
NGO	Non-government organisation
OPD	Organisation of persons with disabilities
RAAB	Rapid Assessment of Avoidable Blindness
SDGs	Sustainable Development Goals
VI	Vision impairment
WG	Washington Group on Disability Statistics
WG-ES	WG Extended Set of Questions on Functioning
WG-SS	WG Short Set of Questions on Functioning
WG-SS Enhanced	WG Short Set of Questions on Functioning – Enhanced
WHO	World Health Organization

1. Introduction

The collection and use of disability data is essential to the design, monitoring and evaluation of disability-inclusive programs and services. There are a range of well-documented tools relating to disability data, as well as a body of practical experience and learning on their application within development and humanitarian programming. However, in the eye health sector, it is only more recently that approaches to disability data have been introduced, and evidence-based frameworks or guidance for the sector are unavailable.

In 2022, the Fred Hollows Foundation (The Foundation) engaged the Inclusion Advisory Group at CBM Global (IAG) to prepare an evidence summary on disability data and eye health. The evidence summary aims to answer the question: *What is the evidence on the collection and use of disability data in eye health programming in low and middle-income countries?*

A literature review was conducted and key informant interviews held with eye health sector organisations in early 2023. A summary of evidence, as well as conclusions and possible ways forward for the sector, are presented in this report.

It is hoped that this report provides a useful basis for the design of disability data approaches in eye health programming in low and middle-income countries (LMICs). It is also intended to inform the design of technical guidance and training on disability data for The Foundation staff and partners.

2. Methodology

This evidence summary is based on a rapid review of literature and targeted key informant interviews, as described in more detail in the Evidence Summary Protocol ([Annex 1](#)).

The review of academic and grey literature was conducted in Scopus, PubMed, Google Scholar and Google, with the inclusion criteria of “disability data” + “eye health” + “low and middle-income countries” (see Annex 1 for search terms). Existing relevant resources produced by or known to IAG were reviewed, including those relating to disability data and eye health, as well as resources relating to disability data in the development and humanitarian sectors and in general health programming.

Key informant interviews were conducted with staff from six international disability and eye health NGOs and one research institute. Interviews included six interviews with The Fred Hollows Foundation staff (to understand their organisational context and experience of disability data); seven interviews with staff from other disability and eye health NGOs; and one interview with a researcher from a disability and eye health research institute.

All data collection and analysis was undertaken by staff from IAG based in Melbourne, Australia, between January and March 2023.

The following limitations to this evidence summary are noted:

- Evidence on the priorities and interests of organisations of persons with disabilities (OPDs) in relation to eye health and disability data has not been captured.

- Ministries of Health or other government agencies responsible for eye health systems were not consulted for this evidence summary, although their perspectives were captured in some of the studies reported in the literature.
- Key international sector coordinating institutions, such as IAPB and WHO, were not consulted for this evidence summary.
- Resources on disability data in development and humanitarian sectors and in general health programming that were known to IAG informed the analysis and discussion of evidence, but have not been reviewed or summarised in detail.

3. Summary of evidence

Overall, there is a limited but growing body of published literature on approaches to disability data within eye health programming in LMICs. Most of the literature reviewed described findings drawn from the eye health programming of two international eye health NGOs: Sightsavers and CBM International. Other eye health NGOs interviewed for this summary reported work on disability data, but had not published their work.

There is no universally accepted definition of 'disability data'. For the purposes of this summary, it will be used to describe all data or information relating to disability. This includes data on individual persons and their characteristics, health situations and experiences. It also encompasses data on health institutions and systems, and on individual components or processes within these – for example, data on the accessibility of hospitals, the participation of persons with disabilities within health system governance or training of staff on disability inclusion.

Evidence from the desk review and key informant interviews is summarised and discussed in the sections below. An annotated bibliography of reviewed literature on eye health and disability data in LMICs is presented in [Annex 2](#). Additional unannotated bibliographies on key background resources relating to disability data in health and disability data in development/humanitarian programming are provided in [Annex 3](#).

3.1. Eye health-related disability data

3.1.1. Findings

This review found that existing literature on disability data in eye health programming is limited to the disaggregation of data on individuals by disability – either within the general population (e.g. surveys seeking to understand the eye health situations of persons with and without disabilities in a given health service catchment area) or among health facility users (e.g. eye health programs seeking to monitor access to services by persons with and without disabilities). Other potential indicators of disability inclusion processes or outcomes were not mentioned in the literature.

Similarly, key informants from eye health NGOs only described efforts to disaggregate data on individuals by disability, and did not provide examples of other types of disability data being regularly collected and used in programming. At the same time, key informants indicated that eye health NGOs are implementing various measures that generate information about disability and inclusion, such as accessibility audits or facility self-

assessments; however, these were not reported as examples of 'disability data'. The reasons for this are unclear; it is possible that informants are working with a narrower understanding of 'disability data' that excludes such information, or that data from these processes is not being routinely captured or analysed.

Work is underway in the eye health sector to develop an indicator framework that aligns to the 2019 World Report on Vision;¹ a set of 22 proposed global eye health indicators has been proposed, which includes a commitment to disaggregate relevant indicators by disability² (but does not include specific indicators relating to disability inclusion processes or outcomes).

3.1.2. Discussion

Whilst this review found a lack of definitions or indicator sets to frame the concept of disability data in the eye health context, two frameworks from outside of the eye health sector were identified. One framework is provided by IAG and the Nossal Institute for the monitoring and evaluation of disability inclusion in general development and humanitarian programs (and also informing DFAT's appraisal of disability inclusion). This aims to measure:

1. The extent of **meaningful participation** of persons with disabilities in the design, management and monitoring of the program/service;
2. Actions taken or processes underway to **remove barriers to inclusion** and/or **provide any required supports** for persons with disabilities; and
3. The extent to which persons with disabilities are **benefiting from outcomes on an equal basis to others**.³

Another framework is provided by WHO in relation to monitoring of disability inclusion in the general health system/sector. This aims to measure:

1. Health system **structures and inputs**, such as disability inclusive policies, accessible infrastructure, and staff training;
2. Service delivery **processes and outputs**, such as the affordability and responsiveness of services to persons with disabilities;
3. Health **outcomes**, such as the coverage of health interventions for persons with disabilities; and
4. Health **impact**, in terms of improved health outcomes and quality of life for persons with disabilities.⁴

An adapted version of WHO's framework, aligned to the context of the eye health sector – and perhaps drawing on frameworks/indicators from the development and humanitarian sector – may provide a sound basis for developing a framework for monitoring disability inclusive eye health.

3.2. Purposes and uses of disability data

3.2.1. Findings

Findings from the literature review and key informant interviews suggest that disability data is being collected and used in the eye health sector to:

- **Understand the eye health needs of persons with disabilities** – for example, population surveys in several countries have found that persons with disabilities (other than visual disabilities) experience significantly higher rates of vision impairment than other persons. These population groups can then be targeted for outreach or inclusion in eye health programs.
- **Identify support requirements and measures to remove barriers to accessing eye health** – for example, understanding the reasons why persons with disabilities are not accessing a particular eye health service, so that changes can be made. This is a key use of data for eye health organisations, however no examples were found of systematic collection of data on barriers and support requirements. Most often, inferences are being made from analysing other data – for example, inferring that costs and transport are barriers to inclusion from data showing that persons with disabilities are accessing eye health outreach camps but not eye hospitals; or inferring that various types of accessibility measures are required from data showing that persons requiring eye health services experience various types of functional difficulties.
- **Evaluate the extent and equity of access to services** – for example, measuring the extent to which persons with disabilities (in addition to vision impairment) within a health service catchment area are accessing the eye health services that they require, and how their access compares to that of other persons. Eye health organisations are increasingly able to measure the extent of access for persons with disabilities; however very few examples were found where data is available to measure equity of access. This is an important distinction for all disability inclusive programming: assessing equity requires understanding not just who is accessing a service, but also who is potentially in need of that service (and, therefore, who is missing out).
- **Evaluate equity of eye health outcomes/impact** – for example, measuring the extent to which persons with disabilities (in addition to vision impairment) are experiencing improved eye health outcomes or reduced incidence of vision impairment compared to other persons. Although this is a clear objective of disability-inclusive eye health programs, examples of this use of disability data were not found in this evidence review. Eye health services or programs are rarely able to track the impact of interventions on a person's quality of life or overall health status, and longitudinal population-level data (which could also provide this information) is rarely available.
- **Support advocacy and awareness raising** – eye health NGOs are using disability data to advocate to eye health service and system stakeholders for policies and measures required to ensure inclusion of persons with disabilities. Advocacy objectives mentioned in the literature and by key informants included using data to demonstrate: the prevalence of persons with disabilities among the health catchment population; the links between disability and eye health problems; and/or the prevalence of disabilities (other than visual) among eye health facility users. In addition, several eye health NGOs reported that the process of collecting disability data had a key (but usually unintended) outcome of raising awareness of disability among eye health personnel and management and generating motivation to take actions for inclusion.

- **Report to aid donors** – aid donors are increasingly requesting funding recipients to report disability data . Only one key informant from an eye health NGO reported that this was a driver of disability data efforts, although noting that it was a secondary driver. (Anecdotally, IAG’s experience suggests that donor reporting is a common driver of disability data efforts in the wider development and humanitarian sectors.)
- **Monitor organisational program impact** – some key informants from eye health NGOs reported having organisation-wide MEL frameworks and systems, for which disability data is required from their eye health programs. Others reported that they did not yet have the capacity and/or intention to routinely collect disability data in their eye health programming, or that decisions to collect disability data would be based on factors external to their organisation (for example, an opportunity to advocate for disability-inclusive eye health system strengthening, or demand from a collaborating eye health service provider to strengthen disability data approaches).
- **Provide information about other disability services** – although a formalised health referral system would typically be based on clinical screening, there is evidence of eye health NGOs using facility-based disability data to provide patients with information about other disability or health services that are potentially relevant and/or local OPDs or other membership groups providing support to persons with disabilities. (See Section 3.8 below for more on referrals.)

Among the evidence reviewed, most data was collected to either understand the eye health needs of persons with disabilities (in the case of population-based surveys) or evaluate the extent of access to eye health services for persons with disabilities (in the case of facility-based data collection).

3.2.2. Discussion

Some key gaps in the design of disability data approaches are:

- Literature and key informant interviews indicate that few eye health programs have disability data approaches that are able to **evaluate equity of access and outcomes for persons with disabilities**. Equity of access is a key indicator of disability inclusion, but measuring it requires comparing rates of access to eye health to the overall population with potential eye health problems. There is now a small body of literature demonstrating that equity can be effectively measured when both facility-level and population-level eye health data are collected using comparable approaches to disability disaggregation (see below). There is also the potential that repeat population surveys (such as the RAAB – see below) can be used in this regard to assess the equity of health outcomes over time.
- Examples of data relating to **support requirements and measures to remove barriers to accessing eye health for persons with disabilities** were not found. Eye health organisations do report providing such supports (such as reasonable accommodations) and implementing measures to remove barriers (such as accessibility measures). It is possible that those measures were designed without using specific data on support requirements or barriers – for example, their design could be based on measures that have proven effective in other comparable contexts. It is also possible that such data was available – for example, in the form of qualitative data from consultations with persons with disabilities – but was not reported as ‘disability data’.
- Although the literature notes the CRPD and SDGs as being highly relevant to informing disability-inclusive approaches to eye health, examples of data being used to **monitor and report against the CRPD, SDGs and other frameworks** were not found. The

reasons for this are unclear. Government respondents, who are responsible for such monitoring and reporting, were not included in this review. It is therefore possible that CRPD and SDG monitoring and reporting of the eye health sector is taking place without the involvement of eye health NGOs. However, it seems more likely – given WHO’s assessment that, globally, data for disability-inclusive health sector monitoring is rarely available⁵ – that disability data is not being used for this purpose in many contexts. This may represent a potential area of focus for eye health system strengthening efforts.

The types of data required in each context, and the systems to support this, will depend on the purposes for which data will be used. Disability data is often collected for multiple purposes; however, the primary identified purpose is often what shapes the design of disability data systems. It is therefore important to deliberately identify and prioritise intended uses of data, and design correlating approaches to disability data. For eye health programs, a key first step may be to articulate an approach to disability inclusion for a particular context or project – based on available evidence, experience from other (eye) health programming and incorporating strategies to remove barriers to inclusion – and then build an approach to disability data around this.

3.3. Disability data sources and collection methods

3.3.1. Findings

Findings from the literature review and key informant interviews suggest that disability data in the eye health sector is being collected through:

- **Population-based surveys** – these include eye health and disability quantitative or qualitative data that is being collected from a particular health catchment population.
 - **General disability data** – Eye health organisations are drawing on secondary disability data from outside of the eye health sector to inform programming. This includes census and statistical surveys providing information on the prevalence of disability and experiences of persons with disabilities in relation to health or other sectors.
 - **RAABs** – Eye health organisations have also started collecting disability data through local eye health population surveys. The most common of these is the Rapid Assessment of Avoidable Blindness (RAAB), which since 2021 has included an optional disability module which incorporates the Washington Group Short Set of Questions (WG-SS – see Section 3.5 below).⁶ This enables disaggregation of key eye health data, allowing analysts to understand the relationship between disability and eye health in a given population. Data from these surveys consistently shows that persons with disabilities experience higher incidence of vision impairment and eye health problems, but are less likely to access eye health services, compared to persons without disabilities. There is also the potential of conducting repeat RAAB surveys including the disability module to measure eye health outcomes in terms of service coverage rates and vision impairment prevalence within a given a hospital catchment population, and to compare these outcomes over time for both persons with and without disabilities.
- **Facility-based eye health patient data** – this includes information on disability collected from persons accessing eye health services, either in hospitals/clinics or outreach camps. This may be collected routinely through a facility’s health

management information system (HMIS) or it may be collected through separate systems (see Section 3.6). It involves personnel somewhere in the patient flow administering a questionnaire relating to disability to every eye health patient. Literature and key informants reported that it has often taken considerable effort from eye health NGOs and hospitals to implement such data collection, due to resourcing requirements, unfamiliarity with disability data tools or the need to demonstrate the value of such data to health system stakeholders (see Sections 3.6 and 3.7). All reviewed examples of facility-based disability data collection included questions to identify disability for the purposes of disaggregation (see Section 3.5), which then enabled analysis of the extent of access to their services by persons with disabilities. Some eye health facilities were reported to be collecting data on use of assistive devices or support requirements, to inform provision of reasonable accommodations or accessibility adjustments to their facility.

- **Health insurance data** – in some countries (e.g. Vietnam), public health insurance data contains disability information which can be linked to an individual patient’s eye health records. This greatly simplifies data collection for health facilities, but the data will be limited by the extent and nature of disability information available.⁷
- **Facility audit/self-assessment tools** – Eye health and disability-inclusive health organisations are developing and using various tools which aim to assess the disability-inclusiveness of health facilities. Most key informants mentioned various forms of accessibility audits or inclusion audits being conducted at health facilities – however these were mostly reported as programmatic tools rather than sources of data. Sightsavers has developed a detailed accessibility guide and audit tool for health facilities.⁸ Researchers in South Africa have developed a rapid disability inclusion checklist for health workers to use to audit their own facilities and identify ways of improving them;⁹ it is currently being adapted by researchers at the London School of Hygiene and Tropical Medicine for testing in low-income countries. Such tools could be further adapted for the specific context of eye health facilities. They could also be considered as sources of disability data; various audit/self-assessment tools are already used in the health sector, including some that calculate a rating or score that is reported against health system strengthening indicators.
- **Focus groups and key informant interviews** – key informants mentioned that focus group discussions or key informant interviews with persons with disabilities or OPDs are taking place occasionally as part of situation analyses and project evaluations, for example, to capture perceptions of the inclusiveness of services. Examples of the types of information collected from these sources were not specifically mentioned.

Overall, there was a strong emphasis in eye health literature and reported practice on collecting population data and disability-disaggregated facility data. These were both reported as being extremely valuable sources of information, but also being resource-intensive and challenging to implement. (Resourcing and process considerations are considered further in Section 3.7.)

Key informants reported diverging views on **whether disability data efforts ought to start first with population-level data or facility-level data**. Some reported first investing in disability-disaggregated population surveys in order to understand the eye health needs of persons with disabilities, and then designing appropriate inclusive interventions. These informants expressed the view that facility-based data is only required later in the program cycle: to evaluate the effectiveness of disability inclusive interventions. Other eye health NGOs have prioritised collecting disability-disaggregated facility data, and using this to demonstrate to facility stakeholders that their existing

patients include persons with disabilities and/or that relatively few persons with disabilities are accessing their services – and therefore that inclusive interventions are required.

3.3.2. Discussion

Disability inclusive eye health programs will require disability data from a range of sources – potentially a mix of all of the above at different stages of programming. Selection of appropriate disability data sources and collection methods should be based around the information requirements of disability inclusive eye health programs.

There is clear evidence in the literature that **measuring equity of access to eye health for persons with disabilities requires both facility-based data and population-level data** for a given health service catchment area, and that both of these must use a comparable approach to disability disaggregation in order to enable comparative analysis. There are relatively few examples where this is the case. Where it has been achieved, it has often been through significant investment in population surveys and health facility data strengthening, and/or through aligning definitions of disability in health facility data to those in already-existing population data. The recent inclusion of the WG-SS in the RAAB and the growing consensus around its use in eye health facility-based data should make this task much easier, and further points towards the rationale for a consistent approach to disability data disaggregation (DDD) discussed in the following section. More should be done to build awareness of the value of this module and encourage its routine inclusion in surveys.

In practice, however, resources are constrained, and those designing and managing eye health programs and services may need to make choices about where to prioritise the resources available for disability data. This will vary for each context, based on assessment of available resources and the potential scope for different types of disability data to support change.

Population-level disability data is highly relevant to inform the design of inclusive eye health services. **Disability-disaggregated eye health population data** (such as that collected by the RAAB) can estimate the prevalence of disability among the population needing eye health interventions and the rate of eye health problems among persons with disabilities. This data is important for determining health resource allocations and informing the design of disability inclusion measures, as well as helping to generate commitment among eye health stakeholders to make services more inclusive. It is also key to understanding existing eye health inequalities and for monitoring changes over time (i.e., where disability inclusion measures are implemented, we would expect to see a closing of the gap between persons with and without disabilities in eye health outcomes over time).

In the absence of eye health-specific data, **general data on disability prevalence** within a population is also relevant. Given that persons with disabilities are more likely to have eye health problems, while also facing additional barriers to accessing health services, disability prevalence data may be used to inform resource planning or advocacy for inclusive health services. However, while this can inform advocacy or planning, it does not give a full picture of the eye health needs of persons with disabilities: it is clear from the literature that rates of eye health problems and access to services among persons with disabilities vary significant across contexts.

Beyond prevalence data, population-level data on the **barriers to accessing eye health services for persons with disabilities and any support requirements that persons with disabilities may require** is also important for the budgeting, planning and design of disability-inclusive eye health services. Such data may come from a mix of sources,

including population surveys, facility assessments or audits, and interviews or focus group discussions. Population data from outside of the eye health sector may also be relevant. For example, data on persons with disabilities' functional difficulties, differential health outcomes, educational attainment, support requirements and use of assistive technologies is available in many countries and can inform approaches to inclusion in eye health.

Disability-disaggregated facility data is essential to monitoring access to services by persons with disabilities. However, where this is collected without comparable population data, the interpretation of this data is difficult. Eye health stakeholders may remain unaware of the extent to which persons with disabilities are not accessing their services, or whether the numbers of persons with disabilities accessing their services reflect the full extent of eye health need in the population. This is a fundamental gap from a rights-based perspective on disability inclusion. (Although it is noted that there may still be context-specific rationales for prioritising collection of this type of data – e.g., demand from a service provider to monitor access to their service by persons with disabilities.)

Some potentially underutilised sources of disability data – that is, sources for which no or few examples were found in the literature or key informant interviews – include:

- **Qualitative data of persons with disabilities** – Although qualitative data is being collected as part of situation analyses, evaluations and research, the nature and relevance of such data was not explained in the literature or key informant interviews. Experience from the general development and humanitarian sector suggests that these are very useful sources of disability data that can help identify barriers to inclusion and the types of supports or accommodations that may be required, and explain the causes of inequities picked up through other data sources. They can also be targeted towards more marginalised population groups whose experiences of eye health might not be reflected in other data sources.
- **Administrative data** – despite health facility administrative data being recognised by WHO as an important source of data for a range of health system strengthening indicators,¹⁰ it was scarcely mentioned in the literature or key informant interviews as a source for data on disability inclusion. Administrative data is often already being collected and managed by health institutions, and could potentially include, for example, data on number of personnel trained, budget allocation, accessibility measures and a range of other indicators relevant to disability inclusion.
- **Follow-up surveys** – examples of surveys that aim to measure changes in health outcomes or quality of life as a result of eye health interventions were not found in the literature or key informant interviews. These could potentially be done as part of evaluations, impact assessments, learning reviews or research where the medium-term health and social impacts of eye health interventions could be tracked for persons with and without disabilities.
- **Feedback mechanisms** – despite feedback mechanisms being a common element of health facility assessment processes, there was no mention of these in relation to disability in the literature and key informant interviews. Feedback mechanisms are a potential source of information about persons with disabilities' experiences of engaging with health services. In order to capture this, they must be accessible and consideration could be given to deliberately encouraging feedback from persons with disabilities in order to further improve services.

3.4. Disaggregating data by disability

3.4.1. Findings

Disability data disaggregation (DDD) involves identifying the individuals within a dataset who have a disability, so that data against other indicators or measures in that dataset can be analysed for both persons with disabilities and persons without disabilities. For example, rates of CSC among persons with and without disabilities can be compared; or access to refractive error services can be compared.

In the eye health sector, literature and key informants report that disability data is being disaggregated by:

- **Self-assessment of functioning** – this has emerged as the most common and widely recommended approach to DDD in the eye health sector, reflecting the wider consensus on disability data (see discussion below) and also the experience in the development and humanitarian sectors. This involves data enumerators asking each respondent or patient a set of questions about difficulties they have in tasks such as moving around, seeing, hearing, communicating, understanding and washing themselves. There are various question sets, ranging from 1 to 48 questions – with the longer ones capturing a more complete range of the types of difficulties that may lead to disability, and therefore being more accurate and inclusive of the full spectrum of disability. The most widely used question sets on functioning used within the eye health sector (and in national statistical data and in the development and humanitarian sector) are those developed by the Washington Group on Disability Statistics (WG). The most commonly used question sets¹¹ in the eye health sector are:
 - **Washington Group Short Set (WG-SS)** (6 questions) – this is the shortest set of WG questions. It is designed to relatively accurately identify persons with disabilities within data collection, whilst being reasonably simple to implement (e.g. in national censuses, for which it was originally designed, where every person in a country is surveyed). Eye health facilities have found it can take 2-5 minutes to administer the 6 questions (in statistical data collection it has been found to take 40-90 seconds). It has been tested and validated in dozens of countries and translated into many languages. There is a very clear and growing consensus around the use of the WG-SS as a preferred tool for DDD in eye health contexts. All eye health NGOs interviewed for this summary reported using the WG-SS, it has been used in almost all studies reported in the literature, it is now included as an optional module in the RAAB, and it is integrated within many national censuses and demographic and health surveys. Eye health organisations are typically using the WG-SS in full and in alignment to the WG's recommended protocols – including following guidance on translation and cognitive testing and using the recommend response 'cut off' in analysis (see discussion below).
 - **WG Short Set of Questions on Functioning – Enhanced (WG-SS Enhanced)** (12 questions) – This includes the WG-SS as well as additional questions on upper body functioning and anxiety and depression. This more accurately identifies some persons with psychosocial disabilities who may not be picked up by the WG-SS. It is a relatively recently developed question set, the use of which has not been documented in the eye health sector. Some eye health and disability NGOs have however started using this a preferred question set in the humanitarian sector.

- **WG Extended Set of Questions on Functioning (WG-ES)** (24 questions) – This includes the WG-SS Enhanced, as well additional questions on pain and fatigue and additional questions on hearing, mobility and cognition. Both the WG-SS Enhanced and WG-ES are intended for use in population-based health or disability surveys where a more accurate understanding of disability and disability-related experiences is required. Some eye health NGOs report trialling using the WG-ES, but results of these trials were not reviewed.
- **WG/UNICEF Child Functioning Module (CFM)** – the WG question sets above are designed for use among adult populations. The WG-SS has been validated for use among children aged 5 years and older. For children aged 2-4, or for a more accurate measure of disability among children aged 5-17, the WG and UNICEF have developed the CFM. This comprises two separate question sets for ages 2-4 and 5-17. The CFM would be recommended for studies looking at the eye health needs of children with disabilities. At least one eye health organisation reported trialling the CFM; however, details of this trial were not provided.
- **Asking direct questions about disability** – this involves asking a person a direct question such as 'Do you have a disability', or whether they have one of a number of commonly understood/legally defined categories of disability or impairment. This relies on the person positively identifying themselves as having a disability, and has been shown to capture only a small proportion of persons with disabilities. However such questions are very quick to administer and may be required in some contexts, for example where a hospital needs to report on service coverage for persons with disabilities based on a government/legal definition of disability. There may also be value in asking such questions where they are already used in other relevant datasets, to enable comparison. For example, several eye health organisation report including questions in facility-based data collection forms that aligned to existing questions in national censuses or health surveys. Given their low accuracy, eye health NGOs have found it beneficial to include WG-SS questions alongside these questions.
- **Linking to external data sources** – in some countries, a person's disability status may have been formally determined through administrative systems outside of health facility or population survey. These systems include disability identification cards, social protection entitlements/concession cards and public health insurance records. As noted above, this greatly simplifies data collection, but the data will be limited by the extent and nature of disability information available through the external system. In many LMICs, these systems may capture only a small proportion of persons with disabilities. There may also be limits in terms of service coverage: for example, one eye health NGO reports that, in Vietnam, public health insurance data included a person's disability status and could be linked to their patient records at hospital; however, public health insurance did not cover eye health outreach camps, and hence this data was unavailable in those settings.¹²
- **Clinical assessment of impairment** – clinical tools are available for screening for various types of impairments by medical personnel, and may be used alongside eye health assessments in contexts where a broader health assessment is being conducted (e.g. in rehabilitation programs, community-based screening or when eye health services are delivered by general hospitals). These tools are used primarily to identify treatment or referral pathways, rather than data disaggregation. Examples of their use in the eye health sector were not found, however it is important to note that medical personnel may have a preference or presumption that this type of approach should be used rather than self-reported functioning.

Literature and key informant interviews indicate that **the WG-SS is by far the most widely used question set in the eye health sector**, and is emerging as a preferred tool for DDD within programs. Direct questions about disability are also used in many contexts, often driven by the need to align to existing disability definitions within a health system or population data. The literature reports that where direct questions are used, eye health NGOs have found it valuable to also include the WG-SS alongside these.

There is an emerging body of literature around the ways in which the WG-SS should be applied. In some of the earlier literature reviewed, eye health organisations had reportedly trialled asking only some of the WG-SS questions (e.g. asking only 3 of the 6 questions) or simplifying the response categories (e.g. prompting a yes/no response instead of the recommended four-response scale). These modifications were reportedly made to streamline and simplify questionnaires, but were found to result in less accurate data that was not comparable across different datasets. More recent literature reports the **use of the WG-SS in its complete, recommended format**, which mirrors experience with this question set from outside of the health sector.

This literature also reports that eye health organisations and researchers have found value in **disaggregating WG-SS data with the vision domain excluded**, due to the close association between difficulties seeing and clinical vision impairment. In an eye health context, the target population is persons with vision impairment or at risk of VI – the focus of disability inclusion is therefore understood as analysing the differences between persons with disabilities (or functional difficulties) other than vision, and those of persons without these disabilities.

Eye health organisations and researchers have trialled different 'cut-offs' in analysis of WG-SS question data. (The cut-off defines how a person's responses to a question set are analysed to categorise them as a person with or without disability within a dataset.) The **WG's standard cut-off for data disaggregation is widely applied and recommended** in the eye health literature: a person who responds 'a lot of difficulty' or 'cannot do' (i.e. the two highest levels of difficulty) to one or more of the questions is defined as a person with a disability. This cut-off identifies the population who are most likely to experience barriers to inclusion or require support or adaptations in order to access services, and is far more specific as a screen for impairments. Its use is recommended for population-based studies and monitoring of eye health access. However, the purpose for which data is being used in a particular case may warrant use of one or more alternative cut-offs. For example, research suggests that where WG-SS data is being used to screen for persons who may benefit from additional health referrals or reasonable accommodations, the lower cut-off of 'some difficulty' is far more sensitive and would capture many such persons who would be missed by the standard cut-off.¹³

3.4.2. Discussion

Disaggregating data by disability is a key source of information to inform disability inclusion analysis and programming. There is an extensive body of literature and practical experience on the approaches to, and complexities of, disaggregating data by disability (the background literature in [Annex 3](#) provides some context on this). This literature is not reviewed here, aside from noting that disability is a multi-faceted concept and, in order to simplify the process of assigning a disability identifier to an individual during data analysis, there is general consensus on using a 'functional approach'. This means that a person self-reports the extent of any difficulties they may have in basic domains of human functioning; if their responses reach the specified threshold for risk of disability, their responses are then used as a proxy for identifying disability and used to disaggregate the dataset by disability.

Over the past decade there has been significant development of approaches to DDD in the eye health sector. There is now a clear consensus that **self-reported functioning is the recommended approach to disaggregating data**. Where existing health systems, administrative data or population data use alternative approaches to DDD, question sets on functioning can and should be integrated alongside these. In eye health or any health context, it is important to work with medical personnel to ensure they understand the rationale for collecting self-reported functioning data (which might otherwise seem irrelevant to them).

The **WG-SS has emerged as the preferred tool** and has been widely used and recommended in population-based and facility-based eye health data collection. The growing consensus and wider use of this tool, including in RAABs and in other relevant datasets, in turn supports a further rationale for its use in order to harmonise data approaches and enable comparison of datasets.

The evidence also supports a clear recommendation that **disaggregation of data on functioning in the eye health sector**, including that generated by the WG-SS and other question sets mentioned above, **should include an analysis of data excluding the vision domain**. This aligns to a perspective that disability inclusion in eye health involves reaching those persons who have other disabilities, in addition to vision impairment. Terminology can get somewhat confusing here; the population group is variously described as 'persons with non-visual disabilities', 'persons with disabilities (other than vision)' or 'persons with additional disabilities (in addition to vision impairment)'. Clear communication is needed around the focus and purpose of DI in an eye health context, i.e. that it is about persons with eye health problems or VI who also have other disabilities.¹⁴ At the level of data analysis, the approach is straightforward: the vision question is excluded from analysis when calculating a 'with non-visual disability' identifier.¹⁵ This can be done in addition to the typical approach, whereby responses against all six WG-SS questions are used to create a 'with disability' identifier in data analysis.

Finally, the **use and trialling of more comprehensive question sets on functioning are underdeveloped in the eye health sector**, although noted by some eye health NGOs as a priority. Tools such as the WG-SS Enhanced and WG-ES should be explored in contexts where a more accurate understanding of disability, health and eye health is required. This should include research and analysis on the eye health situations and access barriers for particularly marginalised groups of persons with disabilities who may not be captured by the WG-SS. This includes persons with psychosocial disabilities and persons with some types of cognitive disabilities. While the use of these tools within eye health facilities may not be feasible (within available resources), their use in population surveys or other research could generate important information about health access and barriers to inclusion for more marginalised groups of persons with disabilities.

3.5. Routine/systematic versus targeted data collection

3.5.1. Findings

The WHO notes that, globally, there is a lack of information about disability in health management information systems (HMISs) and, as a result, disability becomes 'invisible' and under-prioritised in the health sector.¹⁶ The importance of integrating disability data into HMISs is well documented in the broader health sector literature,¹⁷ and was identified

as a key priority by key informants. However, key informants reported that HMIS reform is challenging, requires political will and resourcing and is seen as a longer-term objective.

Findings from the literature review and key informant interviews identified that eye health organisations have trialled various approaches to collecting disability-related patient data at eye health facilities. These have included routine data collection, whereby disability data is collected from every patient accessing a service, and targeted data collection, whereby disability data is collected from a sample or other subset of patients.

The following approaches to **routine data collection** in the eye health facilities were identified:

- **Collection of disability data within HMIS** – relatively few examples are found of disability data being systematically collected through HMISs in eye health facilities, although doing so is identified as a priority by eye health organisations and reportedly significantly streamlines data collection. Key informants reported efforts to integrate disability data into HMISs in Cambodia, Pakistan, India, Senegal, Nigeria, Liberia, Cameroon, Kenya, Mozambique and the Palestinian Territories. Details of all examples were not available; however, of those reviewed, it appears that successful integration of disability data to date has happened where an HMIS is owned and controlled by an individual hospital (i.e. non-government hospitals). Examples of disability data being collected through government HMISs were not found, although preliminary work on this is reportedly underway in some countries (e.g. Kenya and Mozambique).
- **Advocacy for HMIS strengthening** – eye health organisations are advocating for collection of disability data within government HMISs in a range of contexts. Approaches to this include: piloting routine disability data collection in particular hospitals/centres/catchments to demonstrate its feasibility and benefits; focusing efforts on countries/locations where there is already a commitment and systems to collect disability data in related fields, for example in population health statistical data; and focusing efforts on countries where one or more eye health NGOs play a significant and trusted role in public eye health service delivery. Key informants noted that adapting a government HMIS is challenging, and is a medium- to long-term goal of inclusive eye health programs.
- **Routine data collection parallel to HMIS** – where an HMIS is not collecting disability data, many eye health organisations have introduced separate systems to routinely collect patient data. This often involves health facility staff collecting disability data after collecting other data that is routinely entered into the HMIS, and then entering disability data into a parallel reporting system. This system may comprise an Excel spreadsheet, online data platform or paper-based record, with data usually being sent to the eye health NGO funding the work for management and analysis. Eye health NGOs would then use the data for their own internal and external reporting, and for evaluating DI and identifying opportunities to strengthen DI with the health facility. Although this is resource intensive and potentially not sustainable, some eye health NGOs (but not all) reported that this was critical for them to evaluate disability inclusiveness, model good practice, demonstrate feasibility of disability data approaches and raise awareness among health system stakeholders.

While some key informants saw routine facility-based disability data as essential in all cases, others expressed the view that there are many **contexts where routine eye health facility-based disability data cannot feasibly be collected**. This could be due to resource constraints, lack of health facility/system management support, an assessment that available data systems are not fit for purpose, or other contextual factors. Some key informants expressed reservations about the cost effectiveness of

setting up parallel systems for routine data collection, and a preference for more targeted data collection approaches.

The following approaches to **targeted data collection** from eye health patients were found:

- **Collecting no disability data from eye health patients** – some key informants report making a conscious decision not to support parallel disability data collection in eye health facilities, unless there is scope for disability data to be introduced into health facility/sector systems. Instead, they report prioritising efforts to identify and address barriers to disability inclusion, such as through accessibility audit processes, and/or longer-term advocacy for HMIS reform.
- **Sampling patients** – two eye key informants reported exploring approaches whereby disability data at the facility level is collected from a random sample of eye health patients. In one example, this was being done in contexts where the patient load was too high to feasibly collect disability data from every patient. In another example, Sightsavers concluded that sampling can effectively measure levels of access to eye health services by persons with disabilities, but noted that questions remain about whether doing so may have implications for other purposes and benefits of data collection (e.g. providing referrals or building awareness among staff).¹⁸ Neither example has yet generated findings on the validity or relative advantages of sampling approaches.
- **Collecting qualitative or other targeted data** – eye health organisations are also collecting qualitative data relating to disability, including as part of context analysis and evaluation processes. Examples mentioned by key informants include patient satisfaction questionnaires, observation visits to facilities by OPDs, and focus group discussions. Although details of these approaches were not reviewed, experience from development and humanitarian sectors suggests that qualitative information from persons with disabilities can provide highly relevant and useful information to inform the design and evaluation of disability inclusion measures.

3.5.2. Discussion

From the perspective of data robustness, organisations seeking to understand equity of access to eye health services would benefit from using quality disability-disaggregated data that is routinely collected from all persons accessing services. However, this is rarely the case. In many contexts, eye health organisations are making decisions not to collect disability data routinely from all eye health patients. Key informants suggest that these decisions are based on pragmatic assessments of feasibility (e.g. relating to funding constraints or institutional capacity); the value and relevance of such data are not doubted. More trialling and evaluation are needed of eye health monitoring approaches that do not routinely collect patient disability data, to document the relative effectiveness of such approaches in relation to progressing disability inclusive outcomes.

There is a consensus in the literature and among key informants that routine individual patient disability data is most efficiently and effectively collected through an HMIS, rather than a separate system, and that instituting this is a goal of disability-inclusive eye health systems strengthening. There are divergent views around how to reach this longer-term goal, and what approach should be implemented in the meantime. Eye health organisations may benefit from learning from organisations working on disability data within health system strengthening programs outside of the eye health sector. Collaboration outside of the eye health sector may also be beneficial, or indeed necessary in cases where a government HMIS straddles eye health and other health subsectors.

3.6. Feasibility, resourcing and process considerations

3.6.1. Findings

Findings from the literature review and key informant interviews indicated a range of considerations relating to feasibility, resourcing and the design of disability data processes that strongly influence the approach to, and outcomes of, disability data strengthening efforts in each context.

The first set of these considerations relates to **disability data collection processes within eye health service delivery**. Eye health services in LMICs are commonly delivered in challenging and resource-constrained contexts. Patient loads are high, staffing is limited and institutional and health system capacity in relation to data is underdeveloped. Collecting eye health patient data was reported as particularly challenging in the context of outreach clinics/camps, where there may be an extremely high patient load, a disorderly registration process, a reliance on paper-based systems and significant pressure on medical staff to deliver services as efficiently as possible. Disability data collection in hospitals or clinics was seen as more feasible, but nonetheless challenging.

In trying to work around these challenges, eye health organisations have trialled **disability data collection at various points in the patient flow**. Examples from the literature and key informant interviews include:

- **Patient registration desk/form** – whereby disability data is collected alongside the collection of other patient data at the point of registration. This can reportedly create bottlenecks, as registration desks are often busy and under-resourced. Some eye health NGOs have deliberately funded the employment of additional registration staff. Privacy concerns are also raised in some contexts, where the point of registration is very crowded.
- **Eye health nurse/assistant examination** – whereby disability data is collected by the ophthalmic nurse/assistant when first examining the patient. This is reported to allow for more privacy (in some contexts) and for information that may be perceived as personal or sensitive to be collected in a clinical treatment context. However, service providers have found it can place workload pressures on nurses/assistants, and some have reported that asking questions about disability made them feel awkward.
- **Employing additional data collectors** – in India and Malawi, Sightsavers found it beneficial to employ additional data collectors who administered disability data surveys to patients after they had been seen by an ophthalmic nurse/assistant. This was seen as the optimum point, as patients are either waiting to see an optometrist (if required) or on their way home (if they did not have any eye health problems). This required additional resourcing (and therefore may not be sustainable without Sightsavers' funding) but avoided interrupting the patient flow in busy hospital and camp settings. It also mitigated some privacy concerns, as waiting areas were less crowded than the point of registration.
- **Exit/follow-up interview** – one key informant reported collecting disability data via exit interviews, as this was seen as easier to control and manage as it sat outside the regular patient flow. Examples of follow-up interviews conducted some time after attending the eye health service were not found for this review, although one key informant noted that they are exploring this option.

Several eye health organisations report that the **process of collecting data directly from persons with disabilities has important awareness raising outcomes** for the health personnel involved in these tasks. Health personnel have reportedly gained awareness of disability, the diversity of disability and barriers faced by persons with disabilities as a result of being trained on and using the WG questions. In one example, frontline eye health workers reported feeling closer to the disability community and motivated to provide information on relevant services, as a result of their experience of interacting with persons with disabilities as part of data collection.

Literature and key informants reported that **significant resourcing was required** in order to establish disability data collection in eye health facilities and ensure its quality. For example, eye health NGOs have allocated resources to:

- Funding additional staff roles in eye health facilities (e.g. registration staff or dedicated data collectors)
- Collecting disability data themselves
- Designing and delivering training to facility staff (both once-off and repeat/refresher)
- Coordinating and advocating on disability data among government agencies
- Arranging translation and cognitive testing of the WG questions
- Setting up parallel routine data collection systems
- Using their own MEL systems and staff to manage and analyse data
- Commissioning population studies

Among these efforts, there is a reported focus on **training and quality control**. Eye health NGOs reported that training is needed on the specific data collection tools being used (e.g. the WG-SS), as well as on broader disability awareness/sensitivity and inclusive communication. They reported that one-off upfront training was often insufficient; refresher training was also seen as necessary, and follow-up coaching or support from NGO staff was seen as valuable. Eye health NGOs also recommended including management staff in training, as well as data collectors, to build awareness and ownership within management. Quality control efforts, such as conducting spot checks on facility data or reviewing/cleaning data, were also reported to be helpful.

Some key informants reported that, despite investing significantly in training, they still feel that data collection is not being done well or that disability data is not valued by eye health facility staff or management, and hence that the data collected is of low quality. They particularly note the need to explain the purpose and demonstrate the value of WG or other questions on functioning among medical personnel, to whom the questions might appear irrelevant. As one key informant noted, *"Disability data is not at all on the agenda for clinical people – we need to work with them over a long time to convince them. It's quite challenging."* Nevertheless, examples were reported of disability data collection being successfully embedded within an eye health facility, and frontline and management staff starting to use the data and see its value.

Several key informants reported that when disability data is not well understood or valued by health facility stakeholders, data quality falls. Reported examples of this included data being collected only from some patients, questionnaires being abbreviated or filled out directly by enumerators, or data sitting in a hospital system and remaining unused. It was reported that in some cases where disability data was introduced as a requirement of an

eye health NGO or its back donor, it was not seen as intrinsically relevant or useful by hospital staff. Eye health organisations reported finding it helpful to introduce disability data measures alongside or after broader approaches to inclusion, so that awareness of and demand for data are established, or to package disability data together with wider data strengthening work with hospitals. One key informant recommended phasing in incremental disability data strengthening measures over time, so that a start can be made with whatever is feasible, and then quality and complexity can be added over time as increased buy-in and capacity are generated.

3.6.2. Discussion

Eye health organisations have found that the process of data collection – who collects data and from whom, how it is collected, what types of data are collected – matters. Collection of eye health patient data poses significant logistical and resourcing challenges, with implications for the sustainability of disability data efforts, the quality of data and the experiences of patients – including in relation to ethical principles such as privacy. The level of resourcing, training and technical support required will depend on each context, and eye health organisations may have to consider adjusting the approach, speed and scale with which disability data initiatives are introduced in order to best achieve lasting improvements in disability inclusive service delivery.

A determinant of success in efforts to introduce facility-level disability data collection may be the ways in which disability data is presented to health facility or system staff, and the processes used to introduce and communicate disability data collection. Key here is the extent to which eye health personnel and management are committed to disability inclusion, see the value of disability data and understand its role in supporting their service mandate. Being clear on the purpose for which data is being collected (see Section 3.2 above) and ensuring data efforts are driven by a shared commitment and intention to strengthen service equity and inclusion are also likely to be important.

Aside from the benefits of using disability data, the potential for disability data collection processes to raise awareness and transform attitudes among health personnel is an important consideration. The experience of eye health organisations in this regard reflects that of many development and humanitarian workers, who have reported awareness and attitude change among project teams as one of the most common and significant outcomes of using the WG questions.¹⁹ Although it is possible that some of these outcomes could have been achieved through means other than data processes, the potential of data processes to raise awareness and change attitudes and serve as a starting point for taking further action towards disability inclusion should be considered when designing disability data approaches.

The findings presented here and in the previous section (3.5; on routine versus targeted data collection) should all be considered when making decisions about whether and how to design disability data approaches within eye health facilities or systems. Practical guidance for those designing such approaches could draw from these findings, as well as from the experiences of development and humanitarian organisations in deploying disability data mechanisms. (For example, guidance could draw from the general experiences of development NGOs in using the WG questions²⁰ or from the World Food Programme's identified criteria to support decision making regarding DDD²¹.)

3.7. Ethical considerations

3.7.1. Findings

Key ethical considerations relating to disability data and eye health reported in the literature and key informant interviews can be grouped into three categories:

1. **Managing expectations and providing referrals** – eye health organisations have found that when a person is asked questions about their disability, difficulties with daily functioning or barriers to accessing health care, it may create an expectation that some service or benefit will be provided to them in response. Eye health organisations have found it helpful to clearly communicate the purpose of data collection to participants, ensure that measures are in place to provide reasonable accommodations (for persons who require them as part of accessing eye health services) and provide referral information to other services (for persons who may potentially benefit from additional services beyond eye health). As one key informant said, *"We should never be collecting data on disability if we're not able to provide supportive services."*
2. **Cultural sensitivity** – there are mixed reports relating to the cultural sensitivity of asking questions about disability, mostly relating to use of the WG-SS. Some eye health organisations reported that the WG-SS questions were seen as inappropriate or insensitive by data collectors or patients at the facility level. For example, one eye health organisation omitted the question on self-care/washing all over from their patient questionnaire, as this was seen as offensive. Other organisations, however, reported that the WG-SS has been effectively and sensitively used in a range of different cultural contexts, without such issues. One organisation reported that the WG-SS questions were seen as intrusive or insensitive by persons without disabilities primarily from middle-class neighbourhoods, while persons with disabilities were more likely to find the questions appropriate and welcome the opportunity to talk about barriers they experience.
3. **Data privacy** – Examples of privacy considerations reported in the literature and key informant interviews include issues with collecting data in crowded eye health facilities; broader privacy issues with under-developed hospital data systems; and the need to deidentify patient data.

3.7.2. Discussion

Collecting data on disability from individual persons raises several ethical issues. Information about disability can be seen as deeply personal and private, and its disclosure can have real and perceived negative impacts for persons in some contexts. This may be particularly the case in a health context, where historically some persons with disabilities have been denied autonomy or legal personhood in relation to healthcare decisions, including being forced into treatment. Ethical issues in disability data largely arise from the sensitive nature of information being collected and from the experiences of stigma, discrimination and exclusion that many persons with disabilities experience. This is not specific to the eye health sector, and existing guidance available on general ethical practices for disability data collection²² should be largely applicable to eye health contexts.

The three ethical aspects identified above point towards priority areas of data ethics, from the perspectives of eye health organisations working on disability inclusion. Eye health organisations should pay attention to the particular ways that ethical issues may arise the case when a person is asked questions disability and health, or about disability in the

context of health service delivery. For example, a health setting, rather than a general population survey, may prompt a person to raise a range of issues relating to exclusion from healthcare, gaps in essential disability or health services or discriminatory treatment from healthcare personnel. Or the disclosure of health problems may create an expectation that various other health services would be provided, beyond eye care.

Providing information about other relevant services is an important measure. This may require mapping available services in advance and making sure eye health personnel understand their potential relevance to eye health patients. Services may encompass OPDs or self-help groups as well as disability or other health services. It is important to note that a mechanism for providing service information based on WG question data (or other functional data) does not comprise a clinical referral (i.e. a referral made by a health professional based on clinical assessment); rather it is simply providing information about a service to someone for whom it *may* be relevant. (See also the discussion in section 3.5 above on selection of the WG-SS cut-off for referral purposes.)

The reasons for differing reported experiences on the cultural sensitivity of the WG questions are unclear. As the questions have been tested and found to be culturally sensitive in population data collection in many different contexts, it is possible that sensitivities have arisen from the healthcare context in which eye health organisations have been deploying the questions. Other relevant factors may be the level of investment in translating and testing the questions before use, or the way in which data collection is communicated or delivered to patients.

4. Conclusions and recommendations

There is a small but growing body of evidence on the collection and use of disability data in eye health programming in low and middle-income countries. This **evidence** shows that:

- Data from a range of contexts in LMICs shows that persons with disabilities other than visual disabilities experience higher incidence of vision impairment and eye health problems, but are less likely to access eye health services, compared to persons without such disabilities.
- Equity of access to eye health outcomes for persons with disabilities can be measured by: comparing changes in disability-disaggregated eye health population data over time; and/or comparing eye health population data and service user data that use comparable approaches to disability-disaggregation. However, to date, few eye health programs have systems and available data that can measure equity.
- The WG-SS is the most preferred and commonly-used tool for disaggregating eye health data by disability, both at population and health service level.
- Analysis of WG question data for the purpose of disaggregating eye health data should include analysis that excludes the vision domain, due to its close association with vision impairment.
- Eye health organisations perceive that integrating disability data into HMISs at health service level is more efficient and generates more robust data, compared to parallel data collection. However, doing so is challenging and there are relatively few examples.

- Effective collection of disability data at health service level requires staff resourcing, training and management buy-in.
- The process of collecting disability data and engaging with persons with disabilities is, of itself, impactful in terms of raising awareness of eye health staff and driving practice change in institutions.
- Ethical considerations for disability data collection are largely not specific to eye health. Priority considerations for eye health include managing expectations and providing referral information.

There are **gaps in the evidence** relating to:

- Approaches to disability data beyond disaggregation of population- and facility-level data on individuals.
- Key indicators for disability inclusive eye health, and data required to measure these.
- Approaches and tools for collecting data on barriers to inclusion and support requirements.
- Application of other question sets to identify eye health needs and experiences of persons not identified by the WG-SS, including those from more marginalised groups.

There are **outstanding or unanswered questions** relating to:

- The value of collecting of eye health patient data in absence of comparable population data – including differing views on whether this data is a first steps towards inclusion or is only valuable to monitor outcomes post-intervention.
- The respective advantages and disadvantages of collecting facility-based disability data from only a sample of eye health patients, compared to routine data collection from every patient.
- The feasibility and effectiveness of collecting facility-level disability data through parallel systems (outside of the HMIS) – either as a first step towards developing eye health facility/system capacity, or as an indefinitely ongoing measure.

For eye health organisations, the evidence summarised here may provide some directions for the design of disability data approaches, as well as highlighting opportunities to contribute further to the evidence base. While there is a body of evidence guiding DDD approaches in eye health, it is important that programs base data approaches on identified opportunities and strategies to influence disability inclusion in each context. This should include analysis of the existing context of disability data within population surveys, eye health HMISs, public health systems and wider public administration, and assessment of the scope to influence change at health facility and system level.

Potential opportunities to strengthen disability data practice in the eye health sector, either through joint work or sharing of resources and lessons learnt, include:

- Developing an adapted indicator framework for disability inclusive eye health, potentially based on the forthcoming WHO general disability inclusive health indicators
- Developing and sharing common training packages and tools regarding patient data collection (e.g. relating to the WG-SS)

- Developing and sharing tools to collect data on barriers to inclusion
- Harmonising facility-based data collection tools, approaches and messages across eye health NGOs (who are often working with the same hospitals)
- Consulting with persons with disabilities and OPDs to understand their perspectives on the collection, storage, analysis, use and dissemination of disability data in the eye health sector and/or general health sector, and revising guidance and approaches accordingly
- Raising awareness and promoting the routine use of the optional RAAB disability module
- Commissioning studies on the eye health situations of more marginalised or under-represented groups of persons with disabilities
- Coordinating with, and drawing on relevant evidence and lessons learnt from, organisations working on disability-inclusive general/primary health, including in relation to HMIS strengthening
- Creating a platform for regular collaboration, coordination and sharing of resources and learning on disability inclusion in eye health, for example as a working group convened under IAPB and/or IDDC

Notes

¹ World Health Organization 2019, *World Report on Vision*, World Health Organization, accessed from <<https://www.who.int/publications/i/item/9789241516570>>.

² McCormick, I, Mactaggart, I, Resnikoff, S, Muirhead, D, Murthy, G, Silva, JC, Bastawrous, A, Stern, J, Blanchet, K, Wang, N, Yusufu, M, Cooper, A, Gichangi, M, Eye Health Indicators Prioritisation Project Group, Burton, MJ & Ramke, J 2022, '[Eye health indicators for universal health coverage: results of a global expert prioritisation process](#)', *British Journal of Ophthalmology*, vol. 106, no. 7, pp. 893–901.

³ Bush, A, Carroll, A & James, K 2015, [Practice note: collecting and using data on disability to inform inclusive development](#), Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, accessed from <https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf>.

⁴ World Health Organization 2022, [Global report on health equity for persons with disabilities](#), World Health Organization, Geneva, accessed March 14, 2023, from <https://www.who.int/publications/i/item/9789240063600>, p. 244.

⁵ World Health Organization 2022, [Global report on health equity for persons with disabilities](#), World Health Organization, Geneva, accessed March 14, 2023, from <https://www.who.int/publications/i/item/9789240063600>, p. 96.

⁶ Prior to this, Sightsavers has been integrating the WG-SS into RAAB surveys for several years.

⁷ For example, in many countries access to a formal disability determination enabling access to public health or social protection entitlements is difficult to obtain or reflects only a narrow range of disabilities.

⁸ Pregel, A, Smith, K and Bridger, K 2019, *Accessibility standards and audit pack*, Sightsavers Sightsavers, available from the [Sightsavers website](#), <https://www.sightsavers.org/disability/health/accessibility-standards/>

⁹ Hanass-Hancock, J, Willan, S, Carpenter, B, Tesfay, N, & Dunkle, K 2023, *Disability awareness checklist for health care services*, available from the [South African Medical Research Council website](#), <https://www.samrc.ac.za/intramural-research-units/testing-gbv-quality-assurance-tool>

¹⁰ World Health Organization 2022, [Global report on health equity for persons with disabilities](#), World Health Organization, Geneva, accessed March 14, 2023, from <https://www.who.int/publications/i/item/9789240063600>, p. 244.

¹¹ Other question sets based on a functional approach that are used in other context, but not reported in the eye health literature or key informant interviews, include: the Global Activity Limitation Indicator (GALI) (1 question), which comprises a single question about limitations in normal activities due to a health problem, and is used in health surveys primarily in Europe and the UK; and various question sets developed by the World Health Organization for use in health and disability surveys, including the Disability Assessment Schedule (WHODAS 2.0 – 36 questions) and Functioning and Disability Disaggregation Tool (FDD11 – 11 questions).

¹² Bush, A 2017, Disability Inclusive Eye Health Review: A review of lessons learned from CBM's experience implementing inclusive eye health programs in six countries from 2011 to 2017, CBM Australia [unpublished report].

¹³ Boggs, D, Kuper, H, Mactaggart, I, Bright, T, Murthy, G, Hydera, A, McCormick, I, Tamblay, N, Alvarez, ML, Atijosan-Ayodele, O, Yonso, H, Foster, A & Polack, S 2022, '[Exploring the Use of Washington Group Questions to Identify People with Clinical Impairments Who Need Services including Assistive Products: Results from Five Population-Based Surveys](#)', International Journal of Environmental Research and Public Health, vol. 19, no. 7, p. 4304.

¹⁴ As mentioned above, there is now clear evidence showing the link between vision impairment and other non-visual disabilities. As this evidence grows and is disseminated, the need to explain and justify this link may diminish.

¹⁵ For accuracy, this variable may be titled 'with disability (other than visual)' or similar. It is also possible to create two variables: one including the vision domain and one excluding it. This has been done in some studies to enable validation of the WG-SS methodology, and it could allow comparison to other reported data where the underlying dataset is not available or has only been analysed with all domains included.

¹⁶ World Health Organization 2022, [Global report on health equity for persons with disabilities](#), World Health Organization, Geneva, accessed March 14, 2023, from <https://www.who.int/publications/i/item/9789240063600>.

¹⁷ For example: World Health Organization 2022, [Global report on health equity for persons with disabilities](#), World Health Organization, Geneva, accessed March 14, 2023, from <https://www.who.int/publications/i/item/9789240063600>; World Health Organization. Regional Office for the Western Pacific 2020, [Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region](#), WHO Regional Office for the Western Pacific, accessed March 16, 2023, from <https://apps.who.int/iris/handle/10665/336857>; UNICEF 2022, [Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice Guide](#), UNICEF, accessed March 16, 2023, from https://www.unicef.org/media/127496/file/Disability_Inclusion_in_Routine_General_Health_Care_Practice_Guide_2022.pdf.

¹⁸ SightSavers 2016, [Everybody Counts: Disability Disaggregation of Data Pilot Projects in India and Tanzania – Final Evaluation Report](#), SightSavers, accessed March 14, 2023, from https://www.sightsavers.org/wp-content/uploads/2017/09/everybodycounts_brochure_accessible_web.pdf, p. 70.

¹⁹ Robinson, A, Nguyen, L & Smith, F 2021, '[Use of the Washington Group Questions in Non-Government Programming](#)', International Journal of Environmental Research and Public Health, vol. 18, no. 21, p. 11143.

²⁰ For example, see Robinson A, Nguyen L and Smith F (2021) '[Use of the Washington Group Questions in Non-Government Programming](#)', International Journal of Environmental Research and Public Health, 18(21):11143.

²¹ World Food Programme and Trinity College Dublin (2022) [Disability Data: An evidence-informed approach to the use of data for disaggregation in WFP programming](#), World Food Programme, <https://docs.wfp.org/api/documents/WFP-0000139493/download/>, accessed 14 March 2023.

²² For example, see: CBM-Nossal Institute Partnership for Disability Inclusive Development and Research for Development Impact Network (2020) [Research for all: Making Development Research Inclusive of People with Disabilities](#), RDI Network, <https://rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf>, accessed 19 March 2023, Section 2.

Annex 1: Evidence summary protocol

Key learning question

The evidence summary aims to answer the question:

What is the evidence on the collection and use of disability data in eye health programming in low and middle-income countries?

Learning themes and areas of enquiry

The following questions set out themes or areas of learning to be explored through this evidence summary. They are based on preliminary discussions between IAG and Fred Hollows Foundation staff and disability data specialists. It is not expected that all questions in this list will be answered by the evidence summary. Rather, they will inform the design of key informant interview guides, as well as the analysis and report writing process. Emerging themes and areas of enquiry will be added to this list.

4. What capacities, practices and systems relating to disability data collection and use are currently existing among The Foundation staff and partners (including government health service providers)?
 - a. What do staff at The Foundation understand to be disability data and disability inclusion?
 - b. What disability data does The Foundation collect? How is it processed, analysed and reported? Why and how is disability data used across The Foundation? How does disability data relate to The Foundation's approach to disability inclusion?
 - c. What are the key systems, practices and personnel through which disability data is (or could be) collected, stored and shared across The Foundation?
 - d. What do The Foundation staff perceive to be the key opportunities, challenges and considerations relating to disability data and disability inclusion?
5. How can existing standards, guidance, tools and lessons relating to disability data in development and humanitarian programming apply to The Fred Hollows Foundation's work?
 - a. What are the documented guidance and lessons on disability data in development and humanitarian programming?
 - b. How do these guidance and lessons apply to eye health programming? And to The Foundation's organisational and programming contexts?
 - c. What are the key opportunities for the collection and use of disability data by The Foundation?

6. What specific examples and lessons can be drawn from the collection and use of disability data within inclusive eye health, health systems strengthening and disability-inclusive healthcare delivery programs?
- a. How can WGQs be used to help understand the inclusiveness of services among a target population consisting of persons with vision difficulties?
 - b. How is disability data collection best managed at point of service? What resources or systems are used? How does this differ between hospital/centre-based and outreach/camps?
 - c. How does data on functional difficulties collected via the WGQs relate to other tools or measures of disability used within the eye health sector?
 - d. What tools or methodologies are available to assess the extent to which persons with disabilities (other than vision-related disabilities) are accessing and benefiting from eye health services on an equal basis to others?
 - e. How can RAAB and other secondary disability and eye health data best be strengthened or used in eye health programming?
 - f. What examples are there of national/sub-national/facility-level collection of disability data with HMIS's in low and middle income countries? What has worked well, what tools are used, how did this come about?
 - g. What types and sources of data are most useful to inform planning and evaluation of disability-inclusive eye health policies and projects?
 - h. Beyond point-of-service, what other opportunities are there to collect disability data?
 - i. What ethical standards should govern disability data collection in eye health? How are/could these be met in practice?

Desk review protocol

A search of academic and grey literature available in English will be conducted using the following parameters:

- Academic literature: A search of Google Scholar, Pubmed and Scopus will be undertaken.
- Grey literature:
 - Grey literature will be collected through existing resources shared by CBM Global and its partners.
 - A search of Google will be undertaken with the first 3 pages screened.
- Inclusion/exclusion criteria:
 - The search is guided by the question: What is the evidence on the collection and use of disability data in eye health programming in low and middle-income countries?

- To be included, evidence must relate to “disability data” + “eye health” + “low and middle-income countries”.
- If insufficient evidence is sourced through a first search, a second search with expanded criteria may be conducted. This would include:
 - “disability data” + “eye health” OR
 - “disability data” + “health” + “low and middle-income countries”
- Search terms:
 - disability AND (“Washington Group” OR “disability data” OR “disaggregation” OR “disaggregated”) AND (“eye health” OR “eye hospital” OR “vision correction” OR “preventable blindness” OR “vision health”) AND (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”)
 - Date range will be set to last 12 years (2012 – 2023).

Academic and grey literature searches

The review of academic and grey literature was conducted as follows:

- **Scopus** search conducted (date >1/1/2012, fields=all): disability AND (“Washington Group” OR “disability data” OR “disaggregation” OR “disaggregated”) AND (“eye health” OR “eye hospital” OR “vision correction” OR “preventable blindness” OR “vision health”) AND (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – 36 results returned
 - Repeated without (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – 57 results returned
- **PubMed** search conducted (date >1/1/2012): disability AND (“Washington Group” OR “disability data” OR “disaggregation” OR “disaggregated”) AND (“eye health” OR “eye hospital” OR “vision correction” OR “preventable blindness” OR “vision health”) AND (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – 4 results returned
 - Repeated without (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – 11 results returned
- **Google Scholar** search conducted (date >1/1/2012): disability “eye health” “Washington Group” OR “disability data” OR “disaggregation” OR “disaggregated” – first 3 pages reviewed
- **Google** search conducted (date >1/1/2012): disability AND (“Washington Group” OR “disability data” OR “disaggregation” OR “disaggregated”) AND (“eye health” OR “eye hospital” OR “vision correction” OR “preventable blindness” OR “vision health”) AND (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – first 3 pages reviewed
 - Repeated without (“developing country” OR “low- and middle-income country” OR “LMICs” OR “global south”) – first 3 pages reviewed

- Resources were screened for relevance against inclusion criteria (Annex 1: Evidence summary protocol). Literature was excluded if disability data was only briefly mentioned; e.g. where its absence was noted, or its presence was noted only in passing. Literature mentioning eye health but relating primarily to disability data and health was included. Literature presenting findings based on population data on disability and eye health were excluded, except for key resources presenting evidence of the link between disability and eye health issues and explaining methodologies used to generate this evidence.
- Key references cited within each resource were also screened for relevance.
- Existing relevant resources produced by or known to IAG were reviewed, including those relating to disability data and eye health as well as resources relating to disability data in development and humanitarian sectors and in general health programming.

Key informant interviews

Semi-structured interviews will be held remotely with the following key informants, based on interview guides (see annex below):

- The Fred Hollows Foundation staff – selection of program development, advocacy, inclusion, MEL staff (head office); program managers/leads (country office)
- Sightsavers International – Sumrana Yasmin
- Light for the World – Klaus Minihuber (HQ), Janete Conforme (Mozambique)
- Humanity and Inclusion – Gisela Berger
- CBM Global – Danny Haddad, CBM Global; Laura Nicholson, CBM Australia; Vivian Kameloh, CBM Indonesia
- CBM International – Babar Qureshi, Martina Freiberg
- ICEH/ICED (London School of Hygiene and Tropical Medicine) – Islay McTaggart
- World Blind Union – (TBC – depending on relevance)

Interview guide – The Fred Hollows Foundation staff

- Practices and/or experiences relating to disability data at the country program/project level to date - E.g.
 - What is understood to be "disability data"?
 - What data is collected?
 - How is it collected/by whom?
 - How does disability data fit within broader project cycle management and/or MEL?
 - How is disability data used? What are your objectives for collecting data?

- From your perspective, what have been some of the successes, challenges and key learning to date?
- What do you see as the key priorities or entry points for The Foundation (as a whole) to strengthen its practices relating to disability data?
- Are there specific opportunities for the country team?
- What existing guidance on disability data have you used? Are there gaps in that guidance that need addressing?
- Do you have any other comments or examples to share that could help inform this project? Or any questions?

Interview guide – External

- What are your/your organisation's experiences relating to the collection and use of disability data in eye health programming?
 - What types of data are collected?
 - Where/how is it collected?
 - How is disability data used? What are your objectives for collecting data?
- From your perspective, what have been the key lessons learnt to date relating to disability data in eye health programming?
 - Key successes – and what enabled these?
 - Key challenges – and any efforts/ideas to overcome these?
- Targeted learning questions:
 - What types and sources of data are most useful to inform planning and evaluation of disability-inclusive eye health policies and projects?
 - What are some potential ways to assess the extent to which persons with disabilities (other than vision-related disabilities) are accessing and benefiting from eye health services on an equal basis to others?
 - How can WGQs be used to help understand the inclusiveness of services among a target population consisting of persons with vision difficulties? How does data on functional difficulties collected via the WGQs relate to other tools or measures of disability used within the eye health sector?
 - Beyond point-of-service, what other opportunities are there to collect disability data?
 - How is disability data collection best managed at point of service? What resources or systems are used? How does this differ between hospital/centre-based and outreach/camps? Should disability data be collected from all patients, or a sample?

- How do you decide on the most appropriate type of disability data to collect or data methodology to use in each project or context?
- How can RAAB and other secondary disability and eye health data best be strengthened or used?
- What examples are there of national/sub-national/facility-level collection of disability data with HMIS's in low and middle income countries? What has worked well, what tools are used, how did this come about? What is the relationship between data on functional difficulties (WGQs) and other measures of disability used within HMIS's?
- What are the key ethical standards/principles relating to disability data collection in eye health? How can these be met in practice?
- What do you see as the key priorities or opportunities for the eye health sector to strengthen its practices relating to disability data? Any suggestions for collaboration?
- Do you have any other questions, comments or examples relating to this project?

Annex 2: Annotated bibliography

Boggs, D, Kuper, H, Mactaggart, I, Bright, T, Murthy, G, Hydera, A, McCormick, I, Tamblay, N, Alvarez, ML, Atijosan-Ayodele, O, Yonso, H, Foster, A & Polack, S 2022, ['Exploring the Use of Washington Group Questions to Identify People with Clinical Impairments Who Need Services including Assistive Products: Results from Five Population-Based Surveys'](#), *International Journal of Environmental Research and Public Health*, vol. 19, no. 7, p. 4304.

This study in 5 countries analysed the use of the WG questions as a first stage screening to identify people with referral needs relating to clinical impairments and assistive products, including those relating to vision. It compared this data against clinical assessments, and found that the WG questions had only limited-moderate sensitivity and specificity as a screen for clinical impairments. The cut-off "a lot+ difficulty" was highly specific (99%) at screening for vision impairment, but had very low sensitivity (10-39%). The cut-off "some+ difficulty" had good specificity (78-80%) and sensitivity (67-85%). Comparable levels of sensitivity and specificity were also found for hearing, mobility and cognitive impairments. The study also examined the proportion of people identified by the WG questions who were assessed to require clinical interventions, rehabilitation services or assistive products. For vision impairment, the cut-off "some+ difficulty" identified 73-85% of persons needing medical intervention and 65-76% of persons needing rehabilitation or assistive products; the cut-off "a lot+ difficulty" identified 13-40% of persons needing medical intervention and 5-33% of persons needing rehabilitation or assistive products.

For eye health programs, these findings suggest that, if the WG questions are used as an initial screening for eye health needs, they are likely to miss a significant proportion of people with clinical vision impairment. Using the "some+ difficulty" cut-off, with its higher sensitivity, would minimise the number of people missed by such screening. This may be appropriate as a basis for making eye health referrals for people identified in programs that are already using the WG questions, or for use within population studies where identifying 100% of people requiring interventions or services is not necessary. For eye

health programs, the need for clinical vision assessment at screening remains. The WG questions with “some+ difficulty” cut-off could however be used to identify eye health service users potentially requiring referral to other disability-related services.

Bush, A 2017, Disability Inclusive Eye Health Review: A review of lessons learned from CBM’s experience implementing inclusive eye health programs in six countries from 2011 to 2017, CBM Australia [unpublished report²³].

This report presents findings from an internal learning review of six inclusive eye health projects delivered by CBM between 2011 and 2016, including a specific focus on appraising approaches to disability-disaggregated data. The projects reviewed used data either from government and institution-based HMISs or from additionally introduced data collection tools. The main promoted tool was the WG-SS. Relevant findings include that: data collection was labour intensive; additional training and budget was required; additionally-introduced data collection was perceived by project staff only as a donor reporting requirement; disability data collection was most successful where integrated into an HMIS and where a hospital had sufficient independence to adapt systems; disability-disaggregated HMIS data was sometimes incomplete, for example where it was collected only at one level in the healthcare system, or only at centre-based service delivery, or only for patients covered by public health insurance (Vietnam). The report identifies the need for contextually appropriate monitoring approaches, including use of process indicators linked to disability inclusion strategies as a complement (or alternative) to disability-disaggregated service data. It also identifies the need to collect data on barriers to accessing eye health and on the impact of eye health interventions in relation to persons’ quality of life. Where HMISs are not collecting disability-disaggregated data, the report recommends advocacy and capacity building for integration of the WG short set, context-appropriate use of alternative monitoring approaches and consideration that collection of DDD may not be feasible or cost-effective in all contexts.

Jolley, E, Buttan, S, Engels, T, Gillani, M, Jadoon, MZ, Kabona, G, Mohanty, R n., Mohanty, S, Trotignon, G, Woldeyes, A & Schmidt, E 2020, ‘[Prevalence of Visual Impairment and Coverage of Cataract Surgical Services: Associations with Sex, Disability, and Economic Status in Five Diverse Sites](#)’, *Ophthalmic Epidemiology*, vol. 27, no. 6, pp. 429–437.

This article presents findings from five RAAB surveys that also incorporated the WGSS in India, Pakistan and Tanzania. Links between disability, vision impairment and cataract surgical coverage were analysed. WG-SS data was analysed using the “a lot+ difficulty” cut-off in at least one or more of the six domains. Additionally, a “non-visual disability” variable was created by excluding the vision-related WGSS domain from the analysis. Researchers found that, across four different sites, persons with additional non-visual disabilities were 2-10 times more likely to experience blindness or severe visual impairment than persons without additional non-visual disabilities. There were no significant differences in cataract surgical coverage in three of the sites, however in one site coverage was significantly lower for persons with additional non-visual disabilities.

The WGSS was found to allow flexibility of analysis (in functional domains and cut-offs) and to work across different cultures, reinforcing the suitability of this tool for use in the eye health sector. The finding that persons with non-visual disabilities experience higher incidence of visual impairment is significant for the design of inclusive eye health programs and advocacy for inclusive eye health systems and policies. The significant differences in cataract surgical coverage for persons with non-visual disabilities across different sites suggests the need for contextual data collection and analysis.

Jolley, E, Thivillier, P & Smith, F 2014, [Disability Disaggregation of Data - Baseline report](https://www.sightsavers.org/wp-content/uploads/2017/08/Sightsavers-Baseline-Report-Disability-Disaggregation-of-Data.pdf), SightSavers, accessed from <<https://www.sightsavers.org/wp-content/uploads/2017/08/Sightsavers-Baseline-Report-Disability-Disaggregation-of-Data.pdf>>.

This report presents findings from initial steps to set up disaggregation of data by disability in two of SightSavers' projects: an eye health project in India and a NTD project in Tanzania. Findings were based on interviews with project staff and other stakeholders. Relevant findings included that: data from WG questions may not align to data from population census or administrative disability determinations, and hence advocacy with government is needed; that disability data should be included in HMIS and data collection tools; that use of WG questions was effective at sensitising partner staff on disability; that integrating WG questions within electronic HMIS is relatively straightforward, while doing so on a paper-based system is more complicated due to the format and printing costs; and that administration of the WGSS questions in an outpatient department took only a few minutes. SightSavers has gone on to further articulate the approach explored in this report; however, the findings remain relevant and appear to have been confirmed by subsequent experience.

McCormick, I, Mactaggart, I, Resnikoff, S, Muirhead, D, Murthy, G, Silva, JC, Bastawrous, A, Stern, J, Blanchet, K, Wang, N, Yusufu, M, Cooper, A, Gichangi, M, Eye Health Indicators Prioritisation Project Group, Burton, MJ & Ramke, J 2022, ['Eye health indicators for universal health coverage: results of a global expert prioritisation process'](#), *British Journal of Ophthalmology*, vol. 106, no. 7, pp. 893–901.

The paper presents and discusses a set of 22 proposed global eye health indicators (including seven core indicators) that are aligned to the framework of WHO's World Report on Vision. The indicator set was developed through a literature review and inputs from 72 global eye health experts. The set includes an 'equity statement' that all indicators summarising population-based and eye care facility-based data should report metrics disaggregated by disability status, where available. The core indicator on vision impairment prevalence specifies disaggregation by key equity measures (defined to include disability).

While this indicator set has not yet been adopted, the inclusion of a statement on disability disaggregation suggests growing expert consensus on its importance. This would mark a shift from previous global frameworks such as WHO's Universal Eye Health Global Action Plan 2014-19, wherein only sex and age disaggregation were specified.

Mohanty, S, Jolley, E, Mohanty, R, Buttan, S & Schmidt, E 2019, ['Integrating Geospatial Data and Measures of Disability and Wealth to Assess Inequalities in an Eye Health Survey: An Example from the Indian Sunderbans'](#), *International Journal of Environmental Research and Public Health*, vol. 16, no. 23, p. 4869.

This paper reports findings from a population-based survey of visual impairment and coverage of cataract and spectacle services, which was disaggregated by disability using the WG-SS. WG-SS data was analysed using the "a lot+ difficulty" cut-off in at least one or more of the six domains. Additionally, a "non-visual disability" variable was created by excluding the vision-related WGSS domain from the analysis. The study found that the prevalence of blindness among persons with non-visual disabilities was 4.5% compared to 0.3% among persons without non-visual disability. Similarly, the prevalence of severe and moderate visual impairment was 9.2% and 21.1% among persons with non-visual disabilities compared to 2.3% and 7.2% among people without non-visual disabilities. It

also found significantly lower CSC among persons with non-visual disabilities than those without non-visual disabilities. Given these differences, the authors recommend targeted approaches to find persons with additional non-visual difficulties and address the barriers they face, including through engagement of local disability groups.

This study suggests the WG-SS can be usefully and validly applied to identify eye health access gaps for persons with additional non-visual disabilities (in addition to VI). The authors suggest that the significant differences in VI and CSC here could be due the interaction of disability with significant geographical barriers in the study location. This points to the importance of collecting disability disaggregated population data to inform service design in different contexts.

Mörchen, M, Bonn, TS & Lewis, D 2018, '[Towards Universal Eye Health: Hospital-based disability-disaggregated data collection in Takeo province, Cambodia](#)', *Disability and Health Journal*, vol. 11, no. 4, pp. 660–664.

This paper reports on the collection of DDD through the HMIS at a non-government eye hospital in Cambodia from 2011-16. Data was disaggregated using only 3 of the WG-SS questions: those relating to hearing, moving and communicating; the question on vision difficulties was excluded as all patients were assessed for visual impairments, and the questions relating to self-care and remembering/concentrating were deemed to be culturally insensitive to be routinely asked in a hospital setting. In addition, to save time, questions were asked with a binary yes/no response option only. Questions were administered during registration and data entered immediately into the HMIS. Persons with additional (non-visual) difficulties thus identified were found to comprise 2.7% of all hospital patients. Referrals to CBR services were made to 0.36% of patients.

Although the authors note that modification of the WG questions is not recommended, it was deemed necessary in this project in order to make data disaggregation feasible without overburdening staff or requiring additional resourcing. The modifications were seen as a pragmatic approach to making some form of disability data collection feasible and sustainable within the hospital. Despite simplifications, the authors note that the questions may not have been asked consistently. They also note that the binary response options may result in underreporting.

Overall, this report highlights the practical challenges of collecting DDD in hospitals and the need for pragmatic and sustainable solutions. However the non-standard usage of the WGSS also means that comparisons to disability disaggregated catchment population data are not possible, and hence the data collected are not able to answer questions about eye health access and coverage for persons with disabilities.

Mörchen, M, Zambrano, O, Páez, A, Salgado, P, Penniecook, J, Brandt von Lindau, A & Lewis, D 2019, '[Disability-Disaggregated Data Collection: Hospital-Based Application of the Washington Group Questions in an Eye Hospital in Paraguay](#)', *International Journal of Environmental Research and Public Health*, vol. 16, no. 17, p. 3085.

This paper reports on a pilot project to collect disability-disaggregated patient data from a rural eye hospital in Paraguay, using the WG-SS as well as an extended version of the WQ questions including additional domains of anxiety and depression. Using the recommended cut-off of "a lot+ difficulty", WG-SS data found that 16.4% of eye hospital patients had visual difficulties, followed in order of prevalence by communication (9.6%), remembering/concentrating (5.9%), moving (3.8%), hearing (3.5%) and self-care (1.9%). Analysis of data from the extended WG questions identified 3.6% of patients in

the anxiety domain and 1.4% in the depression domain, however with noted measurement errors.

The authors report that identification of significant numbers of persons with functional difficulties other than vision provided a basis for identifying actions required to remove barriers to accessing eye care. This conclusion does not seem borne out by the data. While it may be the case that this data supported advocacy or provided a mandate for taking action on disability inclusion, the data does not identify what barriers need to be removed, nor does it identify which population groups remain unable to access services.

The authors go on to note that institution-based administrative data, such as that collected in this study, may not be helpful in monitoring equity unless it can be compared with general catchment population data. They argue that generating data on the number of patients with disabilities accessing eye hospitals is a first step towards creating more equitable services; however, no evidence is presented supporting this argument, and it contrasts to other literature wherein population data is described as a more useful foundation for action on inclusion.

In relation to the WG questions, the authors recommend the WG-SS be integrated into eye hospitals' HMISs and routinely collected in order to analyse the equity of key outcomes. They advise against abbreviating or otherwise simplifying the WG-SS, as their analysis of data collected via the full WG-SS indicated that any such modifications would significantly reduce accuracy and lead to non-comparable results. Rather, in contexts with limited resources, they propose periodic application of the WG-SS, for example to enable hospital management to monitor changes over time. The use of the extended WG questions is not clearly recommended: the extended set required additional staff training, and the authors report challenges with interpretation of the questions that undermined data quality.

Nesemann, JM, Kandel, RP, Byanju, R, Poudyal, B, Bhandari, G, Bhandari, S, O'Brien, KS, Stevens, VM, Melo, JS & Keenan, JD 2022, '[Association of visual impairment with disability: a population-based study](#)', *Eye*, vol. 36, no. 3, pp. 540–546.

This report presents findings from a population study of persons aged 50 and over in Nepal, which aimed to determine links between visual impairments and other disabilities. The WG-SS was used to identify disabilities. The study found that persons with visual impairment (worse than 6/60) were more likely to have a disability in the walking (OR 5.3), washing (OR 9.4) and communication (OR 5.0) domains. Disabilities in the hearing and memory/concentration domains were more weakly associated with VI. The authors report that the WG-SS was simple to incorporate, added little time, was well accepted by study participants and produced valuable, comparable data.

Oye, J, Mactaggart, I, Polack, S, Schmidt, E, Tamo, V, Okwen, M & Kuper, H 2017, '[Prevalence and Causes of Visual Impairment in Fundong District, North West Cameroon: Results of a Population-Based Survey](#)', *Ophthalmic Epidemiology*, vol. 24, no. 6, pp. 394–400.

This study in Cameroon used the WG-SS alongside assessments of VI, hearing impairment and physical impairments. It found that 30% of people with VI also had hearing impairments, 22% also had physical impairments, and 49% reported having 'a lot' or more difficulties in at least one WG-SS domain other than vision. This evidence further supports the conclusion that persons with disabilities (other than vision) represent a significant proportion of those with VI, and therefore that eye health services must be inclusive of persons with disabilities.

Sanders, R, Gascoyne, B, Appleby, P, Rashida, SA & Jolley, E 2021, '[Eye Health Service Uptake among People with Visual Impairment and Other Functional Difficulties in Bangladesh: A Cross-Sectional Study with Short-Term Follow Up](#)', *International Journal of Environmental Research and Public Health*, vol. 18, no. 17, p. 9068.

This study among cataract and refractive error patients in four districts in Bangladesh explores the relationship between self-reported difficulties in the WG-SS hearing, mobility, self-care, communication and cognition domains and eye health service uptake. Data at hospitals was directly entered into the HMIS; data at outreach camps was recorded on paper and later input into the HMIS. The WG-SS "a lot+" cut off in one or more domains was used to identify persons with functional difficulties, and the vision domain was excluded from the analysis. Translation into Bangla and cognitive testing were completed. Training was provided on disability sensitization, administration of the WG-SS, interview techniques, extracting data from HMIS, and using the mobile data collection app, and data collectors had some practice days to test the tools in hospitals and outreach camps.

The study found that 26.6% of eye health patients reported functional difficulties other than vision (31.4% of women, 21.1% of men). These patients were less likely to take up refractive error services compared to people with same need but with no functional difficulties, and that they were more than twice as likely to access surgical services after attending an outreach camp compared with a hospital facility. No difference was observed in cataract surgical uptake between people with and without self-reported functional difficulties.

The authors note that relatively high levels of access to eye health services for persons with functional difficulties may be due to deliberate outreach and targeting of marginalised patient groups in this context. They also note that study data does not explain the causes of inequality in access to refractive error services; they posit that it may be due to costs, transport challenges or physical accessibility issues.

SightSavers 2016, '[Everybody Counts: Disability Disaggregation of Data Pilot Projects in India and Tanzania – Final Evaluation Report](#)', SightSavers, accessed March 14, 2023, from <https://www.sightsavers.org/wp-content/uploads/2017/09/everybodycounts_brochure_accessible_web.pdf>.

This report presents findings from an evaluation of Sightsavers' two DDD pilot projects in India and Tanzania. In India, extra data collectors were employed to administer the WG-SS and enter data into the HMIS; this was done after registering and being examined by the ophthalmic assistant, and while waiting to see the optometrist. It was found to take 5-8 minutes per patient. (An initial trial found that collecting data at the registration counter was not feasible due to busyness and lack of privacy. One ophthalmic assistant trialled collecting WG-SS data, but reported that this slowed down the process and made him feel awkward.) An electronic HMIS was due to be introduced in the hospital, which was anticipated to solve some of the challenges and potentially obviate the need to employ a dedicated data collector. Spot checks on data were carried out monthly in each hospital and vision centre.

Reported challenges with administering the WG-SS included requiring more time and clearer communication when asking the questions to older adults. Some patients, especially younger persons (and possibly those from middle class areas rather than slum communities), reportedly objected to being asked the questions, despite being told they were to inform project improvements. Clearer communication and provision of IEC materials were recommended to explain the purpose and rationale for the questions.

Conversely, many persons with disabilities were happy to be asked the questions and enjoyed the opportunity to discuss their challenges and seek information or referrals. Data collectors felt uncomfortable because they did not have any services or referral information to provide in such cases.

At the beginning of the project there reportedly were challenges in convincing some stakeholders about the usefulness of the WG-SS as opposed to a single direct question, or a clinical diagnosis, and this was particularly the case with medically trained stakeholders. By the end of the project, programme managers reported no problems with using the WG-SS and described the concept of functional disability as useful for their purposes. The authors attribute this change to careful sensitisation to understand the different definitions of disability and their different utilities. Training was reported to build awareness of disability and change the way staff interact with persons with disabilities. The authors note that regular/refresher training was needed (potentially at six-monthly intervals), and it was essential to involve senior/management staff (as well as data collectors) to ensure buy-in.

Overall, 8.5% of eye health patients in India were identified as having additional disabilities other than vision (using the standard WG-SS 'a lot+' cut-off). A binary "Are you disabled" question was also asked – to enable comparison to local census data – and identified only 0.6% of patients.

Comparison of patient data to existing population sources showed that persons with disabilities were not accessing services in the same proportion as persons who do not have disabilities. Data showed that barriers to access seem to be more important in secondary/tertiary health centres than in primary vision centres, and to affect women with disabilities more than men with disabilities.

The authors found that a key outcome of the DDD collection process was changing attitudes and practices among health providers. Service providers reported feeling closer to the community and obligated to provide information on relevant services. The authors note that this was an outcome of the process of collecting data and engaging with persons with disabilities, rather than being due to the findings of data analysis.

The authors note an outstanding question of whether DDD needs to be collected routinely or can be sampled periodically – and, relatedly, whether the positive attitude and practice-change outcomes that resulted from routine DDD collection might also be brought about when using sampling.

Trotignon, G, Engels, T, Saeed Ali, S, Mugwang'a, Z, Jones, I, Bechange, S, Kaminyoghe, E, Adera, TH & Schmidt, E 2022, '[Measuring equity of access to eye health outreach camps in rural Malawi](#)', *PLOS ONE*, vol. 17, no. 5, p. e0268116.

This paper reports on a study in Malawi measuring equity in access to eye an eye camp, including for persons with disabilities. Patients attending the camp were selected by interval random sampling for a further interview, wherein equity questions were asked including the WG-SS. Data was collected electronically. The study found that 27.5% of eye camp patients had a disability, using the recommended WG cut-off of 'a lot+' difficulty in one or more domains. This compared to 5.6% in existing population data. Excluding the vision domain, 14.2% of participants were considered to have a disability.

The authors report that collecting data from a sample of patients at a more convenient time for them required more work for data collectors but prevented interference with the flow of patients. Collecting additional data after the initial screening was considered the

most optimal point, as by that time the patients were either on their way home (if they did not have any eye problems) or were waiting at the camp for further examination and treatment.

Notes

²³ A related academic paper is available online as Mörchen, M, Bush, A, Kiel, P, Lewis, D & Qureshi, B 2018, '[Leaving No One Behind: Strengthening Access to Eye Health Programs for People With Disabilities in 6 Low- and Middle-Income Countries](#)', *Asia-Pacific journal of ophthalmology* (Philadelphia, Pa.), vol. 7, no. 5, pp. 331–338.

Annex 3: Additional bibliographies

Key reference literature on disability data in health

Missing Billion Initiative & Clinton Health Access Initiative 2022, [*Reimagining health systems that expect, accept and connect 1 billion people with disabilities*](#), MBI and CHAI, accessed March 16, 2023, from <https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/634d9409d12381407c9c4dc8/1666028716085/MBReport_Reimagining+Health+Systems_Oct22>.

Office of the United Nations High Commissioner for Human Rights 2020a, [*Policy Guidelines for Inclusive Sustainable Development Goals: Good health and well-being*](#), accessed from <<https://www.ohchr.org/sites/default/files/Documents/Issues/Disability/SDG-CRPD-Resource/policy-guideline-good-health.pdf>>.

Office of the United Nations High Commissioner for Human Rights 2020b, [*Human Rights Indicators on the Convention on the Rights of Persons with Disabilities: Article 25: Illustrative indicators on health*](#), accessed from <<https://www.ohchr.org/sites/default/files/article-25-indicators-en.pdf>>.

UNICEF 2022, [*Inclusion of Children and Young People with Disabilities in Routine General Health Care: Practice Guide*](#), UNICEF, accessed March 16, 2023, from <https://www.unicef.org/media/127496/file/Disability_Inclusion_in_Routine_General_Health_Care_Practice_Guide_2022.pdf>.

World Health Organization 2022, [*Global report on health equity for persons with disabilities*](#), World Health Organization, Geneva, accessed March 14, 2023, from <<https://www.who.int/publications/i/item/9789240063600>>.

World Health Organization. Regional Office for the Western Pacific 2020, [*Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region*](#), WHO Regional Office for the Western Pacific, accessed March 16, 2023, from <<https://apps.who.int/iris/handle/10665/336857>>.

Background literature on disability data in development and humanitarian programming

Bush, A, Carroll, A & James, K 2015, [*Practice note: collecting and using data on disability to inform inclusive development*](#), Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, accessed from <https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf>.

CBM Global Inclusion Advisory Group 2023, [*Using the Washington Group questions on disability data in development programs: A learning brief*](#), CBM Global Inclusion Advisory Group [unpublished draft report].

Humanity and Inclusion 2019, [*Data on Persons with Disabilities in Humanitarian Action: Collecting quantitative data with the Washington Group Questions - Key findings and*](#)

[recommendations](https://www.humanity-inclusion.org.uk/sn_uploads/document/2019-05-data-on-persons-with-disabilities-in-humanitarian-action-key-findings-and-recommendations.pdf), Humanity and Inclusion, accessed March 14, 2023, from <https://www.humanity-inclusion.org.uk/sn_uploads/document/2019-05-data-on-persons-with-disabilities-in-humanitarian-action-key-findings-and-recommendations.pdf>.

Leonard Cheshire Disability & Humanity and Inclusion 2018, [Disability data collection: A summary review of the use of the Washington Group Questions by development and humanitarian actors](https://www.humanity-inclusion.org.uk/sn_uploads/document/2018-10-summary-review-wgq-development-humanitarian-actors.pdf), Leonard Cheshire and Humanity & Inclusion, accessed March 14, 2023, from <https://www.humanity-inclusion.org.uk/sn_uploads/document/2018-10-summary-review-wgq-development-humanitarian-actors.pdf>.

Robinson, A, Nguyen, L & Smith, F 2021, '[Use of the Washington Group Questions in Non-Government Programming](#)', *International Journal of Environmental Research and Public Health*, vol. 18, no. 21, p. 11143.

World Food Programme & Trinity College Dublin 2022, [Disability Data: An evidence-informed approach to the use of data for disaggregation in WFP programming](https://docs.wfp.org/api/documents/WFP-0000139493/download/), World Food Programme, accessed March 14, 2023, from <<https://docs.wfp.org/api/documents/WFP-0000139493/download/>>.