GUIDANCE NOTE: COLLECTING, ANALYSING AND USING QUANTITATIVE DISAGGREGATED DATA TO ADVANCE INCLUSION AND EQUITY IN DFAT HEALTH PROGRAMS

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1. IMPORTANCE OF DISAGGREGATED DATA

Disaggregated data is the breakdown of data sets by certain categories and subgroups, including, for example, sex, gender, disability, age, ethnicity and other factors. The collection, analysis and use of disaggregated data can play a role in maximising the reach and impact of health programs and advancing gender equality, disability equity and social inclusion (GEDSI) by assisting programs to identify, understand and address prevailing inequalities. While collecting and analysing disaggregated data alone will not automatically result in equitable health outcomes, it is an essential step in identifying inequalities, establishing a baseline and enabling measurement of progress.

Disaggregated data is a central foundation of health equity. When appropriately collected and analysed, disagegated data can be used to:

- Better understand the burden of disease: Calculation of prevalence and proportions can summarise the health status of different groups, and how disease risk and impacts vary between different sub-groups.
- Identify levels of access and utilisation of health services, and the unmet needs of different sub-groups: Data can assist in examining patterns of health service utilisation and identifying areas where different groups of people may face barriers in accessing health services and products.
- Generate information to inform and monitor interventions and support resource allocation: Data can be used to inform health policies and programs to better target those at risk of being left behind, examine if health products and interventions are safe and effective for different groups, support advocacy efforts for improved resource allocation and track unintended consequences experienced by different groups.
- Support workforce planning and professional development: Data can also be used to understand current inequalities in the health workforce and support improvements to workforce equity and diversity.

When utilised effectively, including looking at the above data metrics together, disagreggated data can provide valuable insights into health inequities. For example, looking at data on access to health services and burden of disease data concurrently may be necessary to better understand the factors which may contribute to different health outcomes for different population groups.

This Guidance Note focuses on quantitative data only. It is important to recognise that quantitative data provides only a partial picture, and in many instances qualitative enquiry is needed to further examine data trends, understand how needs are being met and support progress towards greater inclusion. In situations where it may not be safe or posssible to collect disagreggated quantitative data, qualitative data provides an important alternative that may assist in understanding inclusion and equity outcomes for hard to reach groups.

2. PURPOSE AND AUDIENCE

This Guidance Note aims to provide broad awareness of the value of disaggregated data, describe general considerations when capturing disaggregated data and provide an overview of available tools to support DFAT health programs in strengthening data quality, collection, and analysis on gender, disability and social inequalities.

CONTENTS

3. WHAT TO CONSIDER AT EACH STAGE OF DFAT'S PROGRAM MANAGEMENT CYCLE

Australia's International Gender Equality Strategy and International Disability Equity and Rights Strategy outline Australia's commitment to strengthen evidence through high quality gender and disability data collection and analysis, and use of evidence base approaches to inform policies and programs. DFAT's Gender Equality, Disability and Social Inclusion Analysis Good Practice Guide further underscores the Australian Government's commitment to advancing GEDSI and the importance of disaggregated data.

Disaggregated data can and should guide the design, implementation and monitoring of health programs. DFAT's Design and Monitoring, Evaluation and Learning Standards aim to improve the quality and use of MEL products across the program management cycle. Collecting, analysing and utilising disaggregated data requires specific considerations at each stage of the program management cycle, as outlined below.

Planning and design

- Conduct and use GEDSI analysis which includes data disaggregated by sex, age,disability and gender identity , where safe enough to do so[1]. Collecting and analysing disagreggated data of respondents can help you to understand who has informed your analysis including their background and potential biases.
- Identify what dimensions (e.g., sex, gender, disability and/ or age etc.) you will collect data on in your program to help demonstrate progress (e.g., quality, reach and/ or impact), accounting for 'do no harm' considerations, and local data collection and protection laws where applicable. Note, reporting of data disagreggated by sex is a requirement of DFAT programs. Reporting of data disagreggated by disability is encouraged and may be a requirment for some investments (see Disability equity and rights in Australia's international development program- Good practice note).
- Ensure MEL plans and frameworks fully incorporate the collection and utilisation of disaggregated data, using complementary qualitative data to explore the reasons for disparities in disaggregated data. In contexts where health programs are reliant upon limited government data systems or access to data are limited, qualitative data can be of considerable importance. DFAT's Integrating GEDSI into MEL processes within DFAT Health Programs Guidance Note outlines ways to integrate GEDSI into design, monitoring, evaluation, and learning processes and frameworks in health programs.
- Select reliable and statistically sound sources of disaggregated data. For all data sources, it is important to remember that: disaggregated data may be available in the original source material or in the original data set, but unpublished; and data may not be comparable across data sources.
- Plan and budget for accessibility of data processes and the provision of reasonable accommodations. Reasonable accommodations involve providing support, modifications, and/or adjustments to meet individual needs and is necessary to enable full and equal participation. DFAT's Reasonable Accommodation in Development Programs Good Practice Note provides examples and further guidance.

Implementation and performance management

- Maintain clear responsibility, sufficient funding and technical expertise for the collection and analysis of disaggregated data. This includes considering who will analyse data, and how it will be analysed, reported and used (ensuring local capability and process is in place).
- Establish an appropriate data management and governance framework for the security and protection of all data collected as part of the program. Document the restrictions on access, use, storage, retention, and disposal of data assets and provide this information as part of your informed consent processes.
- Collect and analyse disaggregated data at appropriate intervals, including to help guide program adaptations and corrective pivots. The frequency of data collection and analysis should be particularly high in fragile settings, requiring more timely data based on smaller sample sizes and less statistical rigor.

[1] A judgement on what data are safe to collect should be based on contextual analysis and subsequent risk assessment. Consult DFAT's GEDSI Risk Management Good Practice Note for further guidance.

- Engage representative organisations (e.g., organisations of persons with disabilities (OPDs), women's rights organisations and other representative bodies (including diverse SOGIESC [2] groups[3]) in the data collection and analysis, including as part of project MEL or research teams.

Monitoring and evaluation

- Analyse, report and make sense of disaggregated results in program reporting to demonstrate a nuanced understanding of the programs reach and impact. Document any potential limitations and quality issues with the results to support appropriate interpretation and use.
- Communicate disaggregated data to users at different levels within the health system (e.g., operational, management, strategic), representative groups (e.g. OPDs, diverse SOGIESC groups, women's organisations) and broader stakeholders to strengthen accountability and optimal use of the data generated.

4. ENTRY POINTS TO SUPPORT THE COLLECTION, ANALYSIS AND USE OF GEDSI DISAGREGGATED DATA IN HEALTH SYSTEMS

While many health programs may use their own data collection systems for the purposes of monitoring and evaluating their effectiveness, many may also rely on, or seek to support, existing health information systems and data collection processes. This support should consider opportunities to embed data on gender, disability and social inequalities, including by supporting systems to collect, analyse and use disagreggated data as an integral part of data systems. Programs should be mindful that different methods of data collection should consider different approaches that are consignant of what data is needed, the local context and how different groups might be best engaged. For example, point of care data collection would take a different approach to surveys using purposeful sampling or to household surveys. Opportunities to support health systems to collect, analyse and use disagreggated data include:

Identifying data needs

- Identify what data is important, prioritising data that is relevant to local stakeholders and advocating for data on gender and social inequalities where possible. Consider how data will be analysed, reported and used; consider who is involved in the data processes; consider how insights from data collected can be translated into action; and look for opportunities to highlight the value of data on sex, gender, disability, age, ethnicity and/or other metrics.
- Identify gaps, opportunities and options to strengthen data systems and collection methods utilising a GEDSI lens. This includes options to integrate GEDSI considerations into existing data collection efforts including, for example, clinical forms, training forms, surveys etc.
- Consider existing data infrastructure capabilities, including the governance, structures, mechanisms and systems that are available to support the collection, analysis and use of de-identified GEDSI data, including to measure differences in outcomes across population groups. Understanding existing capacity and assessing strengths, gaps, and opportunities across key elements of data infrastructure may help guide capability strengthening efforts.
- Identify opportunities to strengthen capacity for the collection, analysis and use of disaggregated data (if necessary).

Designing data tools

- Ensure standardised instruments are translated into relevant local languages and questions are asked in a culturally-appropriate and sensitive way. Where possible, leverage existing standards and data definitions. Follow the 'collect once, use often' principle to reduce inconsistency across different collections.

[2] SOGIESC is an abbreviation used to describe sexual orientations, gender identities, gender expressions and sex characteristics.

[3] Diverse SOGIESC CSOs may work with some LGBTQIA+ groups more than others which is an important consideration for your data collection and analysis. For example, engaging a generalist LGBTQIA+ CSO may not result in effective outreach to people born with variations of sex characteristics, or engaging a HIV focused LGBTQIA+ CSO may not be effective for reaching all women with diverse SOGIESC.

- **Seek opportunities to strengthen existing infrastructure, guidelines and protocols** with the intention of optimising uptake and supporting sustainability of changes (rather than investing in new tools or guidelines).
- **Use clear terminology, strengthen guidelines and protocols, and invest in capability of project staff, health workers and/or research teams** in the use of appropriate and respectful terminology and approaches; strengthen the understanding of how data collection processes can perpetuate stigma if not undertaken safely; support capabilities in involving people with lived experience; and ensure everyone with access to private/sensitive data understands the significant harm that can occur if certain data are disclosed publicly. A confidentiality statement or privacy statement in local language should be provided.

Data collection process

- **Adopt a 'do no harm' approach and establish safeguards to ensure safe data collection processes**. Promote an understanding of the sensitivities and risks of certain data collection efforts and topics; ensure effective physical, emotional and psychosocial safeguards are in place at all stages of the data collection process; allow for self-identification and avoid making assumptions about an individual's identity; collect contextually appropriate data; obtain ethics approval, informed consent and partner country approval where relevant; and consider data privacy and confidentiality.
- **Promote data security and secure data storage,** including when to de-identify personal data, how to transfer or share data across agencies, and how to appropriately dispose of potentially sensitive data (such as gender identity and ethnicity). Respect data sovereignty by ensuring data collection and storage aligns with the laws, policies, and governing structures of the jurisdiction in which the data is collected.
- **Bring different partners to the table, including those with lived experience, to inform data collection metrics and support data analysis.** This not only ensures quality data is collected but can help navigate challenges such as questions being misinterpreted, poor quality data collection processes, individuals being put at risk, or data processes perpetuating stigma.
- **Develop the collection processes in collaboration with staff who will be responsible for data collection.** Engaging your counterparts in discussions on equity and ensuring processes are locally led is critical. This can also ensure processes are mindful of and responsive to staffing limitations.

Analysis, interpretation and use of data

- **Seek opportunities to consider intersectionality**, noting that multiple intersecting identities can impact health outcomes. This requires breaking down data by different categories and cross-referencing with other demographic variables such as age, sex, gender, disability and geographical location.
- **Incorporate considerations around transparency and accountability** including on how information was collected and analysed, where appropriate inviting those who contributed data to participate in analysis and sense-making exercises, and providing data back to those who informed the data collection processes.
- **Support the use of data in policy dialogue to inform the development and implementation of evidence-informed health policies and programs** which aim to support access to quality health services and products in a way that meets the needs of different sub-groups and reduces inequalities.
- **Exercise caution when comparing datasets:** Any comparisons of data (e.g. between contexts) must be made very carefully and with appropriate explanations in place so that users can understand how and why data might not be directly comparable.

To effectively integrate GEDSI considerations into data systems and processes, it is important to support the meaningful and effective participation of people from target groups with lived experience. This includes providing opportunities for their input at every stage of the data collection process to ensure prioritisation, design, conduct, analysis and sense-making of data collection processes is appropriate and and accessible. A key consideration at each stage is to ensure accessibility and reasonable accommodations requirements have been considered and addressed. This is necessary to support full inclusion and meaningful participation in data collection processes. Examples include providing sign language intepretation at the point of data collection, translating data questions into large print format to enable them to be accessed by a person with vision impairment (including older people), adjusting the start time of a meeting and allowing breaks to support primary caregivers and breastfeeding mothers to engage in data workshops, and providing private, safe, unisex and accessible bathrooms at point of data collection.

Programs should also seek to embed best practice when defining, collecting, analysing and using data on sex, gender, disability, age, ethnicity, indigenuity and other metrics. The following sections provide further insights on how a program may define, collect and analyse disagreggated data.

5. DATA DISAGGREGATED BY SEX, GENDER AND VARIATIONS OF SEX CHARACTERISTICS

Sex, gender and variations of sex characteristics

Text box 1: Defining sex, gender and variations of sex characteristics

Sex is based upon sex characteristics, such as chromosomes, hormones, and reproductive organs. While typically based upon the sex characteristics observed and assigned at birth or infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex assigned at birth. Sex disaggregated data is data that is collected and tabulated separately by biological sex, collected as either sex assigned at birth or sex at time of data collection.[4]

Gender is a social and cultural concept. It is about social and cultural differences in identity, expression and experience as a man, woman, or non-binary person. Data about men and women may include cisgender people and transgender and gender diverse people who identify within binary gender options. Non-binary is an umbrella term describing gender identities that are not exclusively woman or man.[5]

Variations of sex characteristics refers to innate genetic, hormonal or physical sex characteristics that do not conform to medical binary norms for female or male bodies. It includes a wide spectrum of variations to genitals, hormones, chromosomes and/or reproductive organs.[6]

The terms sex and gender are interrelated and often used interchangeably. Both are important determinants of health.[7] However, they are two distinct concepts (see Text Box 1) and it is important to understand the distinctions between these variables, use the appropriate terminology and classifications, and avoid conflating terms.[8] Caution should be exercised when comparing counts for sex with those for gender, noting biological sex is not a proxy for gender.[9] Similarly, data on variations of sex characteristics should not be derived from questions on sex or questions on gender (see Text Box 1).[10]

Sex-disaggregated data is routinely obtained through patient registration, administrative and clinical records, patient surveys and population-based sample surveys. There is growing recognition of the need for health data systems to evolve to represent individuals of all gender identities, including trans and gender diverse people. Some countries have introduced another response category including non-binary as a response category. While this may be a sensitive process, if driven and adopted by partner countries, the integration of additional response categories for sex, gender and sex characteristics has the potential to improve data on access to health services and health outcomes for those who experience diverse gender identity and/or expression.

[4] NHMRC and DoHAC (2024). Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research.
[5] NHMRC and DoHAC (2024). Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research.
[6] Australian Bureau of Statistics (2021). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020.
[7] Vezeau et al. (2025). Gender, Infectious diseases and One Health.
[8] Australian Bureau of Statistics (2020). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables.
[9] The Gender Equality Unit. Differences between Sex Disaggregated Data and Gendered Health Data.
[10] InterAction for health and Human Rights. Forms and data collection

Text box 2: Gender identity and expression in the region

People with diverse sexual orientation, gender identity and expression and sex characteristics (SOGIESC) have always existed in our communities. In the Pacific, for example, Pacific Islanders with diverse SOGIESC hold long-established traditional roles in Pacific cultures, contrary to the assertion that SOGIESC diversity is a colonial imposition.[11] Across the Pacific, pre-colonial Indigenous forms of gender diversity exist, such as vakasalewalewa in Fiji, binabinaaine in Kiribati and fa'afafine in Samoa alongside or concurrently with LGBTQIA+ and other forms of sex, sexual and gender diversity.[12] [13]

Analysis of the local context is important to ensure the history and current experience for people with diverse SOGIESC is well understood. Culture, context and terminology are constantly evolving and preferred phrasing will vary between countries and may change over time. Best practice is to adopt the phrasing recommended by local diverse SOGIESC organisations and communities of people with diverse SOGIESC.

How to collect data disaggregated by sex, gender and variations of sex characteristics

Efforts should be made to design data systems that capture sex as a minimum standard data field to support analysis and reporting by biological sex.

If asking respondents to identify their gender, it is important to use categories that provide options for respondents to clearly identify their gender identity, in a safe way. Collection of sex and gender information can be sensitive for people with innate variations of sex characteristics, or for some trans and gender diverse people. A health service may be the first place a person discloses their gender identity, or one of few places where they disclose their sex assigned at birth or differences of innate sexual characteristics. Some will have experienced non-inclusive data collection and discrimination in the past or have specific concerns including on data confidentiality and protection. It is, therefore, essential to create a safe and affirming space for data collection to reduce risk for individuals. Engaging with local gender experts, and diverse SOGIESC groups and individuals is important in ensuring locally appropriate terminology is used, to avoid gender-biased language and providing options that respect individual identities and preferences. It is also critical to avoid making assumptions about a person's sex and/or gender identity based on indicators such as their name, voice or appearance.[14] Ensure staff are trained to collect data safely from all people, review the design of forms, and consider the layout of intake or reception areas to offer privacy. A diverse SOGIESC organisation being engaged as an intermediary to undertake data collection in a safe location may also support safety and alleviate concerns (where such an organisation exists and there are funds to support their engagement).

Unlike gender data, data on sexual orientation is not usually part of data collection. Consequently, adding questions or options to collect information about diverse sexual orientations is more complicated than similar efforts to collect data about diversity of gender identity. Additionally, diversity of sexual orientation may be particularly sensitive and raise significant do no harm concerns. Seeking data about sexual identity, attraction or behaviour (all elements of sexual oorientation) or data about related issues such as relationship formation may be just as sensitive. Inclusion of questions about sexual orientation on instruments collecting general population data should only proceed after rigorous review. Other contexts may be more appropriate for collection of data about sexual orientation, for example where data is collected amongst a specific population in ways that are considered safe by that population, for example participants in a specific health project or users of a specific health service. Follow ABS (2020) guidance on the question format for sexual orientation.

Examples of questions and responses used by the Victorian Department of Health and the Australian Bureau of Statistics are provided in Text box 2.

[11] Parliamentarians for Global Action. Promoting Inclusion for People of Diverse Sexual Orientations, Gender Identities and Expressions, and Sex Characteristics: A Toolkit for Legislators in the Pacific Region.
[12] Equality Australia. Supporting SOGIESC Equality in the Pacific: Australia's role.
[13] Equality Australia. Supporting SOGIESC Equality in the Pacific: Australia's role.
[14] Australian Bureau of Statistics (2020). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables.

Text box 3: Examples of how to ask about sex, gender and variations of sex characteristics

Examples of questions and response categories for collecting data on sex, gender and variations of sex characteristics

If both sex and gender questions are included in a survey, it is recommended that the sex question is asked first, with a note that a separate gender question will also be asked. Where practical, best practice is to ask both the sex and gender questions on the same page of the instrument.

When collecting data on sex, the inclusion of 'Another term' as a third response option is recommended, noting this recognises where sex is indeterminate or unspecified. Providing respondents with the opportunity to select a third response option and for the respondent to provide a written response (with a free text option) is suggested.

For data inclusive of people with variations of sex characteristics, a separate question is necessary. The inclusion of 'born with a variation of sex characteristics' or 'intersex' as a response option in a sex question, alongside male and female, is not capable of generating reliable or consistent results, because some intersex people identify as male or female, and some do not. People born with variations of sex characteristics may have any gender identity, including a gender identity that aligns with their sex assigned at birth (cisgender) or not (trans or gender diverse, including non-binary gender identities). In summary, the term intersex should not be inserted into questions on sex and/or gender.

Example of collecting data on sex

Question: What was your sex assigned at birth?

- Male
- Female
- Another term (please specify preferred term):

Example of collecting data on gender:

Question: How do you describe your gender?

- Man, boy or male
- Woman, girl or female
- Non-binary
- I use a different term (please specify preferred term):
- Prefer not to say

Example of collecting data on variations of sex characteristics:

Question: Were you born with a variation of sex characteristics (sometimes called intersex or differences of sex development)?

- Yes
- No
- Don't know
- Prefer not to say

Source: Victorian Department of Health (2023). Guidance Note: Inclusive collection and reporting of sex and gender data ; Australian Bureau of Statistics (2020). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables; and InterAction for health and Human Rights. Forms and data collection

The Australian Bureau of Statistics set of tools to standardize data collection on sex, gender and sex characteristics

The standard includes the concept(s), definition(s), questionnaire modules, classification, coding structure, and output categories to be used in interviewer-based and self-enumerated collections, across four variables:

- Sex

- Gender
- Variations of sex characteristics
- Sexual orientation

Source: Australian Bureau of Statistics (2020). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables.

Note: Local terminology should be used where possible, informed by local experts with lived experience. However, structural changes to data collection questions should be minimized to the extent possible.

Analysis of data disaggregated by sex, gender and variations of sex characteristics

At a minimum, data should be analysed separately by sex to help build a better understanding of differences in health needs, disparities and outcomes. To analyse disaggregated data and identify gender issues in health, it is important to compare health outcomes disaggregated by sex, gender and sex characteristics across indicators, considering factors such as access to health services, disease incidence and prevalence, morbidity and mortality rates, and health behaviours, while also considering potential intersections with other social determinants (e.g., age, disability and geographic location). This involves not only looking for differences but also exploring the underlying reasons behind them, often through qualitative research that seeks to understand gender norms and power dynamics that may be contributing to the observed health disparities.

Text box 4: Going beyond sex to consider gendered health data and identify inequalities

Sex disaggregated data in health can indicate the numbers of males and females affected by a particular disease, condition, or cause of death. Data disaggregated by sex assigned at birth is important, particularly in the health sector. It doesn't, however, provide full understanding power relations, gender norms and disparities that exist between women, men, and trans and gender diverse people that also contribute to health outcomes.

What defines gender data?

Gender statistics go further than sex disaggregated data to include insights from additional data collection and analysis, including gender disaggregated data. Gender statistics should ask "the who questions" behind health outcomes: who does the household work, who has power, who makes decisions, who is accessing the health system and who takes on what roles in families and communities. These questions provide insights towards understanding the root causes of health and gender inequities in a population.

Source: UN (2016), Integrating a Gender Perspective into Statistics and The Gender Equity Unit, Differences between Sex Disaggregated Data and Gendered Health Data

6. DISABILITY DISAGGREGATED DATA

Text box 5: The difference between impairment, functioning and disability

Impairment refers to a deviation or loss in body function (including physical, psychosocial, cognitive or sensory functions).[15]

Functioning refers to the interaction between a health condition or impairment and environmental factors, affecting one's ability to perform activities, participate in social settings and live their daily life.[16]

[15] WHO. (2001). The International Classification of Functioning, Disability and Health (ICF).
[16] Ibid.

Disability results from the interaction between impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others.[17]

When to use different kinds of data collection tools/methods

Impairment, disability and functioning are interconnected but distinct terms, as illustrated in Text box 4. A range of tools are available to capture data on these concepts. The most effective and sensitive way of understanding disability is to ask questions about functioning (e.g., difficulties in undertaking specific activities like walking, seeing, or hearing) and where possible, to ask about barriers in the environment that may contribute to those limitations.[18] When choosing a tool, it is important to consider the context, why data is needed, how it will be used, and the time, resources and tools available to capture data. It is also important to consider specific policy and legislation in the local context when considering and selecting appropriate data tools.

A variety of disability data tools exist, each with their own strengths and limitations. This includes, for example, the Washington Group Questions (WGQs) Short Set on Functioning (WG-SS) and the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0). While initially designed to be administered as part of a census, the WG-SS is increasingly used in smaller-scale surveys that collect data at the individual level. It has six questions and is able to be administered in an average time of 1 minute 15 seconds[19] but still has limitations, including that it may miss identifying some populations. The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) will take longer to administer (5 to 20minutes[20]) but is still considered a short and simple to use assessment tool for health and disability, covering 6 domains of functioning. There are other tools being used in health contexts, some of which are outlined in Text box 6. It is important to consider the context and specific data needs to help inform your choice of an appropriate data methodology. WHO provides a more fulsome overview of disability data tools and methodologies, including pros and cons of each tool.[21]

Text box 6: Examples of questions to capture disability status

Washington Group Short Set on Functioning (WG-SS):

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response categories are (a) No – no difficulty; (b) Yes – some difficulty; (c) Yes – a lot of difficulty; or (d) Cannot do at all. While cutoff can vary, a person is generally considered to have a disability if they give a (c) or (d) response to one or more of the questions.

Note, when utilising the WG-SS, it is important to consider age, noting the WG-SS does not apply to children under the age of 5, and may miss many children with developmental disabilities over the age of 5. The UNICEF-Washington Group Module on Child Functioning and Disability is designed to better identify children and young people with disability and validated for use in populations from 2 to 17 years of age.

Source: The Washington Group on Disability Statistics. Note, The Washington Group on Disability Statistics also provides guidance on how to analyse data collected using the Washington Group tools.

[17] UN. (2006). UN Convention on the Rights of Persons with Disabilities, Article 1.
[18] WHO. Data collection and disaggregation on disability: Overview of instruments and methodologies.
[19] Humanity & Inclusion. (2019). WGQs Frequently Asked Questions.
[20] WHO. Data collection and disaggregation on disability: Overview of instruments and methodologies.
[21] Ibid

Disability Module, WHO STEPS Instrument

Preamble: The next questions ask about your health, any long-lasting conditions or illnesses that may restrict your day-to-day activities:

1. Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?
People who chose "Yes" to this question are then asked:
2. Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?
Response field: Yes, a lot; Yes, a little, Not at all.
A person is considered to have a disability if they select Yes to Q1, and Yes, a lot; or Yes, a little to Q2.

Source: WHO STEPwise approach to surveillance – revised Disability module V1.0

Patient self-report disability identifier within health service electronic medical records:

The following question set has been trialed in hospital sites in Victoria, Australia with results indicating strong acceptability. Additional information on the questions, including the preamble to the questions, is included as supplementary material to the source article.

1. Who is answering the questions for the patient? *Patient /Carer*

When answering this question consider what you would expect compared to others of the same age or life stage.

2. Do you /[Does the person you are caring for] have any difficulty doing daily activities*, related to a long-term health condition, impairment or disability?

Yes/ No/ Declined to answer

**Daily activities include all the things you do in your daily life, for example, self-care (washing, dressing); home life (preparing food, tidying); daily organisation (paying bills, managing time and routines); moving around inside or outside your home; participating in play, work or education; relationships with others.*

The following question relates to your long-term health condition, impairment or disability.

3. Which areas do you/ [does the person you are caring for] have difficulty with?

Please select any that apply. You can select more than one.

☐Seeing, even when wearing glasses or contact lenses
☐Hearing, even when using a hearing aid
☐Speaking or communicating with others
☐Learning, understanding, remembering or concentrating
☐Physical activities including moving or feeling part of your body, walking, using your hands and fingers, or stamina/ endurance
☐Mood, managing emotions, socialising or managing behaviours
☐Other.
Optional: What condition or conditions (if known) are the main cause of your difficulties? [Free text

4. Would you like us to know about any adjustments or assistance needed for appointments or when you come to hospital?

Yes/ No/ Declined to answer

If yes, please provide further information about the type of adjustments or assistance needed. You can select from the following examples or provide your own:

☐Finding your way around the health service.
☐Communication (e.g. Auslan or communication device).
☐Understanding information (e.g. extra time for questions, information written down).
☐Decision making and/or consent (e.g. my support person).
☐Mobility and transfers (e.g. a wheelchair or a hoist).

☐Personal care (e.g. help with showering or eating).
☐Sensory or physical environment (e.g. a quiet waiting space or low lighting).
☐Emotional well-being (e.g. things that keep me calm).
☐Other (e.g. pressure care, specific equipment, anything else not captured above).

Source: Rowe, J., Devine, A., Merrick, N. et al. (2025). A patient self-report disability identifier within health service electronic medical records: evaluation of patient, carer and clinician acceptability. *BMC Health Serv Res* **25**, 833.

When capturing disability status for other purposes (i.e., other than for standardised patient data or to produce health statistics), such as to support people's participation in training or other types of programs, it may be more practical to enable self-identification. This process involves asking respondents to voluntarily self-identify if they have functional limitations. The wording of the question, and use of definitions, descriptions and examples should be contextualised, and developed in consultation with people with disability from the local context. The question should still seek information on whether functional limitations or conditions substantially limit life activities or participation in society. It is best practice is to avoid directly asking if a person 'has a disability'. If asking directly about disability, it is important to create a safe environment where people feel comfortable disclosing their disability status. A process that supports people to disclose their disability status can also be accompanied by providing them the opportunity to request reasonable accommodations to support their participation, as outlined in Text box 6.

Text box 7: Tips to support participants with disability to self-identify in training enrolment and monitoring

Clearly explain the activity or event, including the venue type, training format (i.e., face to face or online training), how presentations will be delivered, and expectations of participants (such as to read materials or participate in group discussions).

Ask participants if they would like to disclose any functional limitations or conditions that may affect their participation in the training, using contextually appropriate language. Provide an option not to answer and clearly communicate the purpose of data collection (such as to make adjustments to support their participation in the training program, or to monitor their experience in applying training content in their workplace). Inform participants of the steps taken to ensure privacy and confidentiality of information.

If disclosure seeks to support participation in training (rather than post-training monitoring/evaluation), it may be better to avoid asking about disability directly and focus on needs, such as by asking "Are there any accessibility needs we should be aware of?" Or "What accommodations or modifications, if any, would help you fully participate in this training activity?".

Provide a list of accommodations that will be available, as well as those that can be available on request, such as: accessible restrooms and seating options; digital adjustments to ensure materials are compatible with assistive technologies and alternative formats such as real-time captioning for training sessions, large print, audio, or Braille; and sign language interpretation. Follow up and consult with participants who request accommodations to ensure that accessibility adjustments are effective and meet their needs.

How to collect contextually appropriate data on disability

When asking about disability it is important to be aware of potential stigma surrounding disability and sensitive to how different cultures may understand disability. Person-centred language aligns with the UN Convention on the Rights of Persons with Disabilities and is a useful starting place for language on disability. It is important, however, to understand that preferences for language and terminology may differ across contexts or across identities. It is critical to ask people with lived experience about preferred terminology. Consulting people with disability and local Organisations of Persons with Disability (OPDs) in accordance with the 'nothing without us' principle is essential in developing approaches. People with disability should be supported to play a role in key stages, for example:

- Advising on the most appropriate data collection tools, methods and associated definitions, language and explanations, and testing questions.

- Advising on safe and accessible processes to collect data for people with different types of impairment. This can support the use of appropriate communication methods, ensure locations for data collection are accessible, and that people with disability feel comfortable participating.
- Participating as facilitators or enumerators, and training people administering tools on how to ask questions using appropriate, neutral and respectful language.

How to analyse and report disability disaggregated data

When analysing disability disaggregated data to produce health statistics and identify trends, it is important to break down the data by different impairment categories, cross-referencing with other relevant demographics such as age, sex, gender and geographical location. Stratification can be used to analyse data by impairment type, severity, and other relevant factors to understand unique health needs within different disability populations.

7. AGE DISAGGREGATED DATA

Age is a basic core demographic variable and forms the basis of most analyses of the characteristics of a population; collection of age and birth date is generally accepted as good practice in health-related data collection processes.[22] Despite its wide usage as a classification variable, standardisation and comparability is difficult at both the national and international levels given the use of different age classifications.[23] For example, the UK displays cancer incidence in five-year age groups, while the US provides specific information on infant cancers.

In 1982, the United Nations (UN) set out provisional guidelines on standard international age classifications. This provided three different approaches to age classifications which provide differing levels of detail, requiring different statistical capability and effort.[24] In 2001, the WHO recommended the use of 5-year groups from birth up to the oldest reached age (100 years or older).[25] Although this recommendation has remained the suggested standard since then, it is not universally applied. There is also support for more nuanced groupings for younger ages to reflect neonatal disease burden.[26] Approaches to standardisation of age groupings are presented in Text box 8. Regardless of categories, the Australian Bureau of Statistics recommends that age groupings should start and end with digits ending in 0 or 5 to ensure a clear and consistent way of dividing populations for statistical analysis.

Text box 8: Approaches to standardisation of age groupings

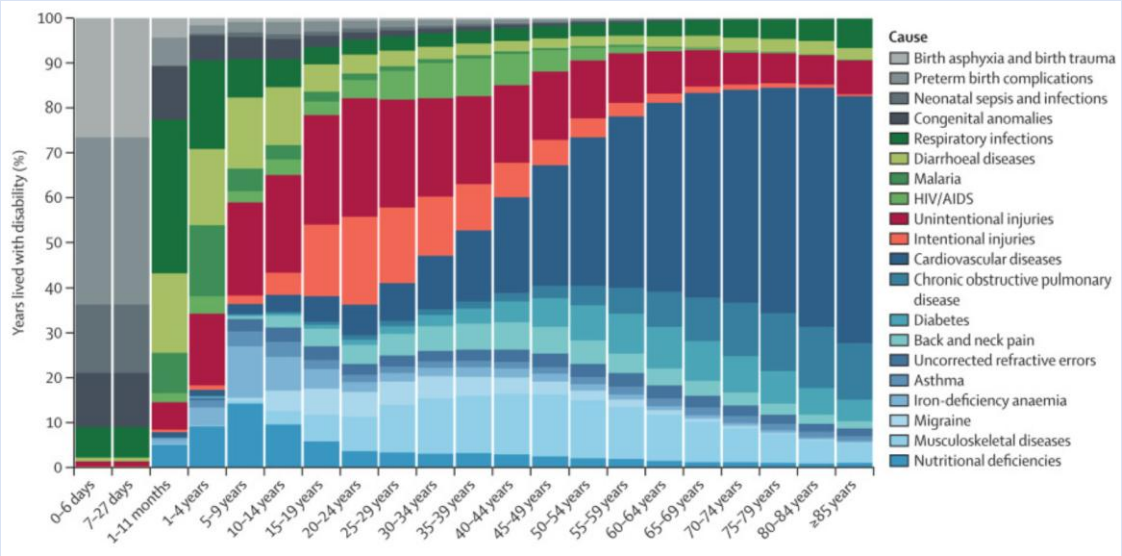
Call for standardised age-disaggregated health data

The COVID-19 pandemic resulted in massive, rapid, cross-country analyses of reported cases, but the variations in age groupings made these analyses difficult, highlighting the urgent need for standardised age categories for reporting. This call for standardisation recommends age groupings of 5 years for all health data, except for those younger than 5 years, where rapid biological and physiological changes justify a finer disaggregation.

Source: Diaz et al. (2021). A call for standardised age-disaggregated health data. *The Lancet Health Longevity*.

[22] Australian Bureau of Statistics. (2014). Age Standard, 2014, Version 1.7.
[23] UN Department of International Economic and Social Affairs. (1982). Provisional Guidelines on Standard International Age Classifications.
[24] Ibid.
[25] World Health Organization. (2001). Age standardization of rates: a new WHO standard.
[26] Diaz et al. (2021). A call for standardised age-disaggregated health data. The Lancet Health Longevity.

Years of age lived with disability by recommended standardized WHO age groups in 2019



Source: The Lancet informed by [WHO methods and data sources for country-level causes of death 2000–2019,](#) WHO (2020).

It is important to recall that countries have varying needs and capabilities for data collection, storage, analysis, utilisation and presentation and the age at which a person is considered an infant, child, youth, adult or older person may vary according to context. Local age categories may be more important or relevant to consider than international recommendations. It may be necessary to also consider what specific age groupings may be helpful for your area of work. For example, capturing data on age related incidence and prevalence for infant cancers may look different to non-communicable diseases. Methodological or statistical limitations may also have an impact (e.g., some surveys may require larger sample sizes and therefore larger age groupings).

8. ETHNICITY AND INDIGENEITY DISAGGREGATED DATA

Defining and classifying ethnicity and Indigeneity

Ethnicity and Indigeneity are distinct but overlapping concepts. As data classifications, they are complex concepts noting they are socially constructed, subjective and can change over time.

There are a range of different terms used to discuss and refer to ethnicity or Indigeneity such as Indigenous Peoples, tribal peoples, ethnic minorities and First Nations peoples (see Annex C for a Glossary of Terms). It is important to recognise the use of context-specific terminology and groupings that may not be transferable. For example, while 'First Nations' is commonly used in Australia when referring to Aboriginal and Torres Strait Islander people, this language is not commonly used in the Pacific, with Indigenous People commonly referred to as 'Pacific Peoples' or Pacific Islanders', and further classified into country groupings. In some countries, Indigenous People may constitute the majority, and in others the minority. Text box 8 illustrates the use of terminology and ethnic classification in a study comparing cancer mortality for the two main ethnic groups in Fiji's population to identify ethnic disparity.

Text box 9: Study of cancer mortality by ethnicity for women in Fiji

A study into cancer mortality in Fijian women aged 30 to 69 compared differences between two ethnic groups Indigenous Fijians (i-Taukei), who comprise the majority of Fiji's population (62%), and Fijians of Indian descent (31%). The study found incidence of cancers higher in i-Taukei Fijian women than in other countries and double that of Fijian women of Indian descent. It notes that high incidence and late diagnosis contribute to high cancer mortality, and that differences between i-Taukei and Fijians of Indian descent women required further investigation.

Source: Dearie et al. (2023). [Ethnic disparity in cancer mortality in adult Fijian women, 2013-17](#).

Ethnicity and Indigenous status may be used when referring to minority groups, migration status and/or nationality, which are at times used as proxies for one another in different contexts. It important to ensure clarity on the differences and purposes of data related to ethnicity in a specific country context. For example, administrative or clinical data may seek to capture data for all ethnic groups in a country to identify trends in health outcomes and identify ethnic disparities in access to health services (as illustrated in Text box 8). Some systems or studies may examine trends in the health of migrants (and migrant subgroups, such as migrants from low- or high-income countries), with a focus on nationality, to understand how migration can be a positive or negative determinant of health. Clinical trials may capture data on ethnicity or race to understand genetic variations among ethnic groups. Other data capture may seek to identify ethnic minority groups in a population to identify socio-economic factors, culture or geographical influences on health outcomes, as illustrated in Text box 10.

Text box 10: Study of mental health among ethnic minorities in Vietnam

Vietnam has fifty-four recognised ethnic groups, the largest being the Kinh (Viet) people (87%); the other 53 groups are considered ethnic minority groups who are concentrated in the mountainous highland regions.

Studies on mental health in children were largely performed in urban or rural settings, with a lack of inquiry among ethnic minority adolescents in Vietnam. A recent study was carried out to measure the rate of depression, anxiety and stress among ethnic minority adolescents and identify relationships between demographic characteristics, behaviours and childhood experiences, with different mental health conditions.

The study focused on adolescents of ethnic minorities who study in boarding schools guided by cultural practices that emphasise freedom and autonomy and lack of constraints by societal norms and collective regulations. Under this study, the focus on ethnicity sought to examine how culture affected psychological characteristics and in turn the prevalence of mental health conditions.

The study found high prevalence of mental health conditions and adverse childhood experiences among ethnic minority adolescents when compared with available data obtained from studies carried out in geographic locations where Viet people predominantly reside.

Source: NA Vinh et al. (2024). Mental health among ethnic minority adolescents in Vietnam and correlated factors: A cross-sectional study.

Data collection processes and principles

Ethnicity and Indigeneity data are often classed as special category data under data protection legislation, and some counties may have laws that prohibit the collection of data pertaining to ethnicity due to sensitivities. It is important to understand what data can be legally collected and comply with relevant legislation. It is also important to adhere to Indigenous data sovereignty principles which emphasise the right of Indigenous People to control and own their data.

Ethnicity and Indigenous status are subjective and deeply personal, and systems should allow for self-identification, noting self-reporting is considered the best and most practical data collection method.[27] Individuals may identify with multiple ethnicities or may identify differently over time, making classification difficult. The application of the 'Do No Harm' principle must be applied. For example, while self-identification is commonly the best approach, in some contexts where ethnicity is defined by law, self-identification can be harmful. It is important to be attentive to possible situations of harm and adapt what and how information is collected, stored, shared, retained, disposed, and used accordingly.

Comparability of data sets

It is important to clarify the dimensions being captured through surveys and health systems, and to consider how/whether to group ethnicities together and how this may affect comparability over time. Systems should be

[27] AIHW. (2013). National best practice guidelines for collecting Indigenous status in health data sets.

flexible enough to account for changing identities. Use of very specific groupings increases the risk of disclosing information about individual people, while aggregating ethnicities can hide differences between ethnic groups. It is best to avoid using binary categories which have little analytical value as they can mask significant differences in outcomes between different groups.

Using the total population as the comparator in the analysis is the most 'neutral' approach. This approach does include an element of comparing an ethnic group against itself, as the group will be in the comparator. Exercise caution when making comparisons of ethnicity datasets, given the subjective nature of ethnicity and cultural differences in the terms used to describe ethnic groups. It is important to acknowledge the context behind ethnic classifications, such as historical and political factors, will often shape these categories. Understanding such context supports an appropriate framing of analyses and helps to prevent the misuse of ethnicity data. Any comparisons must be made very carefully, and with appropriate explanations in place so that users can understand how and why data might not be directly comparable.

9. OTHER METRICS FOR QUANTITATIVE DATA DISAGGREGATION

While not explored in detail in this Guidance Note, there are other metrics and layers of disaggregation that are important to consider including, for example, geographical location, and migration status. Additional layers of disaggregation should be determined by local context and the data needs of the health program.

10. ANNEXES

ANNEX A: Glossary of terms

Term	Definition
Sex	A person's sex is based upon their sex characteristics, such as their chromosomes, hormones, and reproductive organs. While typically based upon the sex characteristics observed and assigned at birth or infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex assigned at birth.[28] See also the glossary entry on sex characteristics.
Gender	Gender is a social and cultural concept. It is about social and cultural differences in identity, expression and experience as a man, woman, or non-binary person. Non-binary is an umbrella term describing gender identities that are not exclusively women or men.[29] Gender identity and expression can vary across cultures and change over time and are not always aligned with sex assigned at birth. Gender includes the following concepts: • Gender identity: Each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen ,modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms[30] • Gender expression: Each person's presentation of the person's gender through physical appearance – including dress, hairstyles, accessories, cosmetics – and mannerisms, speech, behavioural patterns, names and personal references, and noting further that gender expression may or may not conform to a person's gender identity.[31] A person's gender expression may also vary depending on context.
Sexual orientation	Each person's capacity for profound emotional, affectional, and sexual attraction to, and intimate and sexual relations with, individuals of a different gender, the same gender, or more than one gender.[32]
LGBTQIA+	An acronym that recognises a diverse range of sexualities, genders and sex characteristics: Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual, plus (+) other identities. These are identity categories that may or may not be relevant in all countries and cultural contexts.[33]
Sex Characteristics	A person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty.[34] [35]

[28] NHMRC and DoHAC (2024). Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research.
[29] Australian Bureau of Statistics. (2021). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables
[30] Yogyakarta Principles (2006). Introduction to the Yogyakarta Principles.
[31] Yogyakarta Principles (2006). Introduction to the Yogyakarta Principles.
[32] Yogyakarta Principles (2006). Introduction to the Yogyakarta Principles.
[33] Edge Effect. We don't do a lot for them specifically. A scoping report on gaps and opportunities for improving diverse SOGIESC inclusion in cash transfer and social protection programs, during the COVID-19 crisis and beyond.
[34] Yogyakarta Principles (2006). Preamble (YP+10)
[35] IOM. SOGIESC Glossary of Terms.

Term	Definition
Variations of sex characteristics	Variations of sex characteristics refers to people with innate (that is, variations that someone is 'born with') genetic, hormonal or physical sex characteristics that do not conform to medical binary norms for female or male bodies. It refers to a wide spectrum of variations to genitals, hormones, chromosomes and/or reproductive organs.[36] These variations create risks or experiences of stigma, discrimination and harm.[37] People with innate variations of sex characteristics form a diverse population and use varied language to self-describe. This includes, for example: a) intersex; b) innate variations of sex characteristics; c) intersex variation, status, person, characteristics or trait; or d) diagnosis specific language.[38] [39] it is important to note that many variations of sex characteristics are not evident at birth, and people may not be aware they were born with a variation of sex characteristics until puberty or later in life. it is also possible that a person may never know that they were born with a variation of sex characteristics.[40]
Trans (transgender) and gender diverse	Transgender people (often shortened to trans, or trans men or trans women) are people whose gender does not align with their sex assigned at birth. Trans people may identify as men or women, or may identify within or outside of the gender binary. Gender diverse refers to the full range of gender options including non-binary, gender fluid and agender. [41] Identities such as vakasalewalewa, binabinaaine and fa'afafine may include elements of trans and gender diversity, but also of sexuality, which may transcend the distinction between sexual orientation and gender.
Diverse SOGIESC	SOGIESC is an abbreviation of Sexual Orientation, Gender Identity and Expression and Sex Characteristics (SOGIESC). All people have SOGIESC. Diverse SOGIESC includes people whose SOGIESC does not exist within normative frameworks.[42] This term may be preferred over LGBTQIA+, as it includes culturally specific identities that do not correspond to Western LGBTQIA+ identities. Preferred phrasing may vary between countries and may vary over time. Best practice is to adopt the phrasing recommended by local diverse SOGIESC CSOs and communities of people with diverse SOGIESC.[43]
PIDSOGIESC	PIDSOGIESC+ is a term that extends the concept of SOGIESC (Sexual Orientation, Gender Identity, Expression, and Sex Characteristics) to include additional layers of diversity for Pacific Islanders. The PIDSOGIESC+ framework acknowledges the importance of regional and cultural context, as well as specific issues affecting diverse communities. It offers a nuanced and inclusive framework that takes into account cultural diversity, intersectionality and holistic inclusion.[44]
Disability	Results from the interaction of impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others.[45]
Impairment	Refers to a deviation or loss in body function (physical, psychosocial, cognitive or sensory)[46]

[36] Australian Bureau of Statistics (2021). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020.
[37] InterAction. (2025). Who are intersex people?
[38] InterAction. (2025). Who are intersex people?
[39] InterLink. Resource Hub – Language
[40] NHMRC and DoHAC (2024). Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research.
[41] Source: Edge Effect
[42] Dwyer, E. et al. (2021). The Only Way Is Up. UN Women Regional Office for Asia and the Pacific, Bangkok.
[43] UN Women Regional Office for Asia and the Pacific, 2021. Diverse SOGIESC Rapid Assessment Tool
[44] Parliamentarians for Global Action. Promoting Inclusion for People of Diverse Sexual Orientations, Gender Identities and Expressions, and Sex Characteristics: A Toolkit for Legislators in the Pacific Region.
[45] UN. (2006). UN Convention on the Rights of Persons with Disabilities, Article 1.
[46] WHO. (2001). The International Classification of Functioning, Disability and Health (ICF).

Term	Definition
Functioning	Refers to the interaction between a health condition or impairment and environmental factors, affecting one's ability to perform activities, participate in social settings and live their daily life.[47]
Organisations of People with Disability (OPD)	OPDs represent the interests of their members with disabilities. They are led by people with disabilities and have the mandate to advocate for the realisation of their human rights and lobby for the consideration of their interests. OPDs can exist on a local, national, regional, and/or international levels. Some OPDs may be specialised to advocate for specific groups among persons with disabilities (e.g., women and girls with disabilities, children with disabilities, Indigenous Persons with disabilities etc.) or for specific impairment groups (persons with visual impairments, psychosocial impairments, Deaf people, physical impairments etc.), others may focus on certain topics (e.g., education, health, political participation, gender, etc.). The term Disabled Peoples' Organisation (DPO) can be found. It means the same, but the term OPD is increasingly common and more widely accepted.[48]
Ethnicity	Refers to the shared identity or similarity of a group of people on the basis of one or more distinguishing characteristics. These characteristics include: • A long shared history, the memory of which is kept alive. • A cultural tradition, including family and social customs, sometimes religiously based. • A common geographic origin. • A common language (but not necessarily limited to that group). • A common literature (written or oral). • A common religion. • Being a minority (often with a sense of being oppressed). • Being racially conspicuous.[49]
Indigeneity	Refers to the state or condition of being Indigenous, specifically relating to the First Peoples of a particular region and their historical relationship with the land and waterways. It encompasses a broader concept of identity, culture, and relationship to land and heritage.
Indigenous Peoples	The descendants of populations who inhabited a country or geographical region at the time of conquest, colonisation or establishment of the present State boundaries. They retain some or all of their own social, economic, cultural and political institutions, irrespective of their legal status.[50]
Tribal Peoples	Having social, cultural and economic conditions that distinguish them from other sections of the national community. Their status is regulated wholly or partially by their customs or traditions or by special laws of regulations.[51]
Ethnic Minorities	Ethnic minorities as groups, in a non-dominant position, whose members – being nationals of the State – possess ethnic, religious, or linguistic characteristics differing from those of the rest of the population and with a need or desire to preserve their unique culture and identity.[52]
First Nations Australians	Aboriginal and Torres Strait Islander peoples are Australia's first people. Both Aboriginal and Torres Strait Islander peoples, use terms such as 'First Nations Australians', 'First Australians' or 'Aboriginal and/or Torres Strait Islander peoples'.[53]

[47] WHO. (2001). The International Classification of Functioning, Disability and Health (ICF).
[48] CBM Inclusion Advisory Group. Organisations of Persons with Disabilities (OPDs) - Inclusive Participation Toolbox
[49] Australian Bureau of Statistics. (2019). Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG).
[50] Source: Ninti One Limited.
[51] Ibid.
[52] Ibid.
[53] Ibid.

ANNEX B: Additional resources

- Australian Bureau of Statistics. (2020). Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables: This tool aims to standardise the collection and dissemination of data relating to sex, gender, variations of sex characteristics and sexual orientation.
- CBM Inclusion Advisory Group and Nossal Institute for Global Health. (2025). Using the Washington Group solutions on disability data in development programs: This learning brief is for development practitioners and project managers interested in collecting and using disability data in their programs. It offers practical guidance with suggested approaches to overcoming common issues and concerns, with a focus on the Washington Group questions.
- ICRC. (2023). Sex, Age and Disability Data Disaggregation Framework: The Framework provides guidelines regarding sex, age and disability disaggregated data (SADDD) to support unified data collection and use of these data for comprehensive population diversity analysis and better programming.
- NHMRC and Department of Health and Aged Care (DoHAC). (2024). Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research: The Statement aims to improve health outcomes by ensuring that sex, gender, variations of sex characteristics, and sexual orientation are considered throughout all stages of health and medical research and to promote a more inclusive and equitable approach to research, particularly for underrepresented groups, and to ultimately improve health care for all.
- Plan International Australia, CBM Australia and Nossal Institute for Global Health. (2015). Collecting and using data on disability to inform inclusive development: Provides key issues and principles to consider when collecting disability inclusive data.
- SPC, Nossal Institute for Global Health and the Pacific Group on Disability Statistics (2025).Pacific Regional Guidebook on Disability Statistics: This guidebook provides information on disability concepts and measurement in the Pacific region, guidance on disability data collection tools and their use and translation considerations, and detail on data analysis and dissemination strategies.
- The Washington Group on Disability Statistics. Implementation Guidelines: How to use the WG questions: These guidelines provide an overview of the WG methodology actualized in the development of disability data collection modules for censuses and surveys.
- UN Women. Making Every Woman And Girl Count: UN Women Chair this program which is now in it's second phase. Several resources are available under this program including a Final Annual Report for Phase 1 in addition to a brief on Phase 2 of the program.
- UN Women Data Hub. (2021). Counted and Visible Toolkit: A compilation of tools and mechanisms used by several countries to produce intersectionally-based evidence to inform gender-responsive policies and catalyze actions to leave no one behind.
- UN Department of Economic and Social Affairs (2014). Integrating a Gender Perspective into Statistics: A manual produced by the UN Statistical Division outlining the requirements for a gender perspective in statistics.
- UNFPA (2014). Methodological Guidelines for the Gender Analysis of National Population and Housing Census Data: Methodological guidance to make increasingly effective use of the data from Population and Housing Censuses as related to gender issues.
- UN Women and United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) (2021). Intersectionality resource guide and toolkit: This toolkit aims to help both organizations and individual practitioners and experts to address intersectionality in policies and programmes. Of particular relevance to this guidance note is Tool 2 (see Page 37) which outlines 'Key considerations for creating safe spaces'.
- WHO. Data collection and disaggregation on disability: Overview of instruments and methodologies: A paper summarising the purpose and pros and cons of prominent tools for collecting disability disaggregated data.
- WHO Health Inequality Monitor: Demonstrates how disaggregated data can be used to show how health is experienced differently by people of different ages, sex, and other characteristics, from different countries. Itcontains health inequality monitoring evidence, tools, resources and training.