

Developing Measures of Intersex Status/Differences in Sex Development at the Population Level

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Is the “I” for Invisible?

Biological factors:

- Intersex populations are defined by biological variations
 - Variations can be of *any* sex characteristic, internal and/or external
- Intersex variations typically thought of as low frequency
 - Highest estimates of sex variation are 1.7%
 - Genital difference (ambiguity) much less common, 0.02-0.05%

Is the “I” for Invisible?

Legal and Psychosocial Factors:

- Most people are assigned either male or female at birth
- Medical treatment has emphasized a binary approach:
 - Concealment of diagnostic and treatment history prioritized
 - Early surgical intervention standard treatment, especially for people with genital difference
- Shame and concealment are common experiences among intersex populations

However, most people with intersex traits report that they are willing to disclose this information in a survey setting.

(Tamar-Mattis et al., 2018)

But how, and where?

- As a measure of sex, intersex/DSD status is a demographic measure
- Intersex/DSD status is also associated with a range of medical conditions
- When provided with the option, most people with intersex traits will choose “intersex” as a component of their gender identity (Rosenwohl-Mack et al, 2020)
- Many surveys that assess intersex status do so as an option for sex assigned at birth (on the original birth certificate)
- Several community and advocacy groups have recommended a separate intersex status question

Conclusion 2:

Intersex status is an important component of demographic status, private medical information, and an aspect of identity. Although there are barriers to disclosure, people appear to want to disclose their status.

Because of historical, legal, and medical factors, almost no person in the United States is assigned intersex at birth. Therefore, **it is inappropriate to assess intersex status primarily with an “intersex” response option for sex assigned at birth**; however, when sex assigned at birth is asked, it may be appropriate to include “prefer not to answer” or “do not know” options.

Recommendation 6:

When the National Institutes of Health seeks to **identify people with intersex traits or differences of sex development** in clinical, survey, research, and administrative settings, they should do so **by using a standalone measure that asks respondents to report their intersex status**. They should not do so by adding “intersex” as a third response category to a binary measure of sex.

Intersex/DSD Status Measures with the Strongest Evidentiary Support

- Very little evidence on the quality of intersex/DSD status measures is available.
 - Only one study asked community members for feedback on a measure (Tamar-Mattis et al., 2018)
 - Three studies used variations of recommended measures in LGBTQ+ population-based surveys with low non-response rates but wide range of positive responses (Medina and Mahowald, 2021; Price et al., 2021; Bradbury-Sullivan, 2021)

Intersex/DSD Status Measures with the Strongest Evidentiary Support

- Three question stems have been tested in population-based surveys, but little evidence is available to assess their relative quality:
 - *Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?*
 - *Were you born with a variation in your physical sex characteristics? (This is sometimes called being intersex or having a difference in sex development, or DSD.)*
 - *Have you ever been diagnosed by a medical doctor with an intersex condition or a difference of sex development'?*

Conclusion 3:

Based on the best available evidence, community guidance, and expert opinion, intersex status can be measured using the following question:

Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?

Yes

No

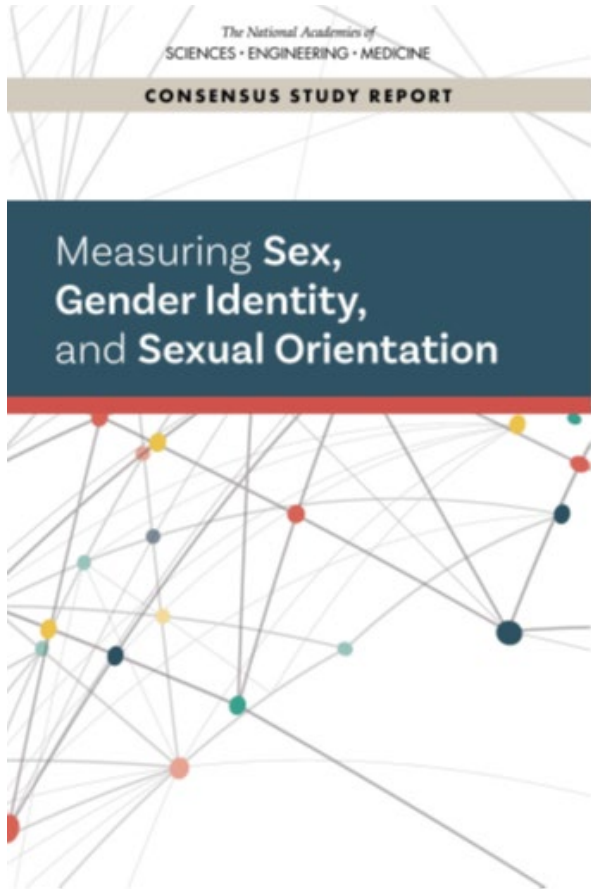
(Don't know)

(Prefer not to answer)

Intersex/DSD Status: Topics for Future Research

RECOMMENDATION 7: To improve the quality and inclusivity of current measures of intersex status, the National Institutes of Health should fund and conduct research on the following topics:

- The use of a single-item intersex/DSD status question
- The relative quality of the three measures of intersex/DSD status identified by the panel
- The effects of using terminology such as “intersex” or “DSD” or definitions of these terms in question stems or supplemental text
- The prevalence of “intersex” as a gender identity term among people with intersex traits
- Proxy reporting of intersex/DSD status, particularly by parents



Thank you!

Access The Report:

<https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

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