

Improving the health of trans people: the need for good data



The health of transgender (trans) people (those with a gender identity which differs from the sex assigned to them at birth) is a major equity issue worldwide, with trans people experiencing poorer health outcomes than cis (non-trans) people.¹ Data science approaches are improving public health, but trans people are at risk of not benefitting from these advances. Furthermore, specific ethical concerns regarding the application of such approaches to trans people's data will require careful communication and engagement with the trans community.

High quality data are required to monitor health trends, assess health needs, and evaluate the effects of policies and other interventions. However, valid sources of quantitative data for trans people can be difficult to find. Population-based surveys are limited by the lack of standardised survey items used to identify trans respondents, and are often too small to provide meaningful samples of trans people.² Research to inform health needs often relies on trans-specific service usage data,³ which can be of relatively poor quality and makes direct comparisons with cis populations difficult. This scarcity of data inclusion at the population and health-care system levels excludes trans people from health-care debates,⁴ potentially widening existing health inequalities. Additionally, there are considerable global inequalities—as far as we are aware, all previous national surveys of trans people's health have been done in high-income rather than low-income or middle-income countries.¹

Public health research and policies are increasingly harnessing routine administrative data sources, since primary data collection is expensive and often does not provide representative information. We argue that trans people could benefit from this approach; however, inherent challenges exist regarding the use of administrative datasets, which are unique to the trans population and might require the structure of existing datasets to change (panel). We acknowledge that our list is not exhaustive, and additional problems (particularly relevant to low-income and middle-income settings) include infrastructure, resources, and personnel constraints.

Given the ethical and legal complexities of the issues identified, public health professionals and

epidemiologists considering the way forward must realise they need to engage with the trans community, as well as medical ethicists, legal professionals, and others. Despite ostensibly having protection under equality legislation in many parts of the world, many trans people continue to face discrimination at work and when accessing health-care services.¹ Understandably, many trans people might not wish their trans status to be disclosed in routine data sources without their knowledge. A participatory approach with a strong emphasis on community engagement is essential to ensure their voices and concerns are heard and acted upon.^{7,8} Involvement of third sector organisations is likely to be of particular benefit because such organisations are often aware of the potential opportunities of harnessing data, and have been encouraging and facilitating data collection regarding sexual orientation and gender identity within the private sector.⁹

Panel: Challenges for using data science to improve health of transgender people

Binary classification

Most existing administrative datasets include only two sexes, excluding or misclassifying non-binary individuals (who have a gender identity which is neither exclusively male nor female). However, modifying these categories needs careful consideration, since changes can disrupt the ability to compare data over time and across data sources.

Ascertainment

Most administrative data do not include reference to a past sex to avoid outing people;⁵ records of transgender (trans) people will be coded either as the sex they were assigned at birth or that with which they identify, with no identifier of their trans status.

Consent

Use of opt-in consent procedures, while probably acceptable to most people,⁶ might only reach those already in contact with trans-specific services. Identification of trans people within routine datasets without consent would require careful consideration of individual right to privacy to ensure acceptable safeguards are included.

Confidentiality

The likelihood of inadvertent disclosure and breach of confidentiality might be high. Trans people contribute approximately 0.3–0.5% of the world population,² but far fewer are openly trans and in contact with services, making them a highly identifiable group within population datasets. Subgroup analysis (eg, considering trans men, trans women and non-binary individuals separately) would reduce numbers further, and disclosure risk must be considered.

Probabilistic matching

When linking individuals across databases, often only those deemed to have a high statistical likelihood of being the same person are matched and included in the analysis. Many trans people might have their sex or gender recorded in different ways across different datasets, so are more likely to be coded as a non-match and therefore omitted from the data analysed.

Working with the trans community to establish frameworks for safe and acceptable usage and linkage of routine administrative data that consider the concerns of trans people has huge potential to improve understanding and service delivery for this population—an example includes a Dutch study which used data linkage to more accurately quantify risk of breast cancer in the trans population.¹⁰ If the public health and wider research community do not act, while the rest of the population continue to reap the benefits of big data, trans people's health might continue to be compromised.

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