On the Just and Accurate Representation of Transgender Persons in Research

Alexis Dinno
Portland State University, alexis.dinno@pdx.edu

Molly C. Franks
Portland State University

Jenn Burleton
TransActive Education & Advocacy

Tyler C. Smith
TransActive Education & Advocacy

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ON THE JUST & ACCURATE REPRESENTATION OF TRANSGENDER PERSONS IN RESEARCH

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ALEXIS DINNO, ScD, MPM, MEM

in collaboration with

Molly C. Franks
Jenn Burleton
Tyler C. Smith
About me and why I am here...

Transgender
Transsexual
Drag performer

Epidemiologist

Social justice activist

My collaborators are likewise:
  sexual and gender minorities
  public health professionals
  motivated by social justice

We share dissatisfactions with portrayals of transgender persons in research.

Aside: basics of epidemiology

Epidemiology is the study of health and disease *in populations* with the aim of improving health in those populations.

Many of the figures epidemiologists produce are derived from two concepts:

*Prevalence*: how common a health condition is at a moment in time

*Incidence rates*: how fast new cases of the health condition arise in a population; also: risk of the health condition in the population

The more sophisticated epidemiologic measures are based on these two concepts.
A critical distinction between epidemiologists and clinical health researchers is located in the *population perspective.*

Put briefly, a small change in *risk*—even one so small as to be meaningless to an individual—implies a large number of cases when multiplied across a whole population.

Epidemiologists are therefore concerned with policies, planning and environmental change: the causes of prevalence and incidence in a population are *not* the causes of being a case in an individual.
Epi has largely failed transgender persons

What are the top causes of death in transgender populations?

What are the top health concerns faced by transgender persons?

We can parse out the prevalence and incidence of many causes of health, morbidity and mortality by race/ethnicity, by economic conditions, by geography, by sex, and age…

…but we cannot present even limited pictures for transgender persons.
Why?

We have identified several biases in the academic health literature:

• Transgender is studied as disease outcome, rather than as a population of persons with their own particular health determinants and concerns

• Transgender persons are far more likely to be studied as vectors of HIV and other STIs

• We—epidemiologists—simply tend not to represent transgender persons in basic epidemiologic research. (And when we do we often create more problems.)
Principle 1 for representing of transgender

1. Transgender should not be subsumed within a question about sex.

Example:
Are you (pick one): ( ) Male ( ) Female ( ) Transgender

Results:
• Transgender persons excluded from analyses of male & female experience
  —or—
• Invites the unjust exclusion of transgender from representation when transgender persons opt to respond “Male” or “Female”

Transgender persons typically are also male or female.
Principle 2 for representing of transgender

2. Do not include transgender identity in questions about sexual orientation.

Example:
Are you (pick one): (  ) Heterosexual (  ) Homosexual (  ) Transsexual

Results:
• Perpetuates blindness toward the health concerns of transgender people
• Directs attention away from the health needs of transgender and gender non-conforming children, for whom gender is often salient long before sexual orientation.

Every person has both gender identity and sexual orientation.

Gender identity intersects with sexual identity (and age, family relationships, religion and many other signifiers).
Principle 3 for representing of transgender

3. *The timing of transgender identity and transitions in gender identity during an individual’s life should be represented.*

Example:
Have you taken cross-sex hormones? ( ) Yes ( ) No
How old were you when you first began taking cross-sex hormones?

Results:
• Includes diversity in when during the life course gender shifts
• Captures transgender experiences as children that may bear on health in different ways than transgender experiences during adolescence or adulthood
• Potentially represents many different transitions (not just hormones!)
Principle 4 for representing of transgender

4. Do not prioritize any mode or direction of gender transition or transgression.

Example (for an female-born transgender person):
How long have you wanted to be a man?

Results:
• Builds tacit assumptions about a transgender person’s developmental trajectory
• May subtly exclude some transgender persons from representation

Transgender persons do not necessarily want the same transitions. Wanting to not be a woman does not necessarily equate with wanting to be a man.
Principle 5 for representing of transgender

5. Although inclusiveness is desirable, avoid “select all that apply” modes of soliciting different flavors of transgender identity in structured surveys.

Example:
Are you (select all that apply):
( ) Transsexual  ( ) Transgender  ( ) Cross-dresser
( ) Pink-boy  ( ) Boy-girl

Results:
• Misses lady-boy, hijra, stone butch, gender-fuck, fluid, third gender, drag queen, drag king, reconstructed femme, gender-queer, gender-punk, radical faerie, Sister of Perpetual Indulgence, and many more…

Transgender is a rich domain: identify specific parts relevant to health.
Principle 6 for representing of transgender

6. *Simple and straightforward language is desirable.*

Example:
People may identify themselves as transgender if they do not conform to other people’s expectations based on their birth sex.

Do you identify yourself as transgender: ( ) Yes  ( ) No
Principle 6 and children

Age-appropriate language is important. This may present a challenge, and may require qualitative inquiry into children’s language around gender.

For example, in my personal experience, very young English-speaking children on the West Coast of the USA very readily understand and use the term ‘boy-girl.’ However, different languages, times and places may render this term meaningless.

Language to identify both transgender & cisgender will grow more complex as children mature and their social realities gain nuance.
Parsimony in survey design: 0 questions

Surveys are expensive, and each question costs real money.

We recommend the following *minimal* set of questions pertaining to gender identity, prioritized according to the number of questions about transgender permitted on a survey.

When no questions about transgender will be explicitly included, at least two questions should be asked to identify the respondent’s sex over the lifetime:

1. What was your sex at birth?
2. What is your sex currently?

Surveys may naturally include intersex responses.
Parsimony in survey design: 1 question

A straightforward yes or no question asking if the respondent self-identifies as transgender should be included. This question should be separate and in addition to a question about the respondent’s sex:

Do you identify yourself as transgender: ( ) Yes   ( ) No
Parsimony in survey design: 2 questions

A follow up question for those answering ‘Yes’ to transgender self identity:

When were you first aware that your gender identity either did not match your body or other people’s perception of your gender?
Age: _____ ( ) As long as I can remember.

This will help understand the role of transition and transgender identity on health across the life course.
This will also facilitate the differentiation of the ‘As long as I can remember’ and those transgender persons who developed transgender identity in adolescence or later.
We have no prevalence, incidence or more sophisticated measures for the health of transgender populations in the USA because we are not collecting the most basic data required for the numerators and denominators. (Are we collecting these data elsewhere?)

Without these basic measures, we cannot assess the changes in risk of death and disease among transgender persons that result as a consequence of, for example, organizational, institutional and governmental transgender anti-discrimination policies that affect the health of transgender populations.