

Why IRBs must scrutinize collection of LGBTQ information

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While the health needs of lesbian, gay, bisexual, transgender and queer (LGBTQ) people are becoming better understood by the U.S. medical community, members of this population remain vulnerable as research subjects due to the stigmas that may accompany revealing their sexual and gender minority identities. Such information may be disclosed because it is protected under a patchwork of laws.

At the same time, many leading LGBTQ health institutions do not have standardized training materials that speak explicitly to these ethical and safety concerns in a research context. The AMA is supporting the creation of a model training for institutional review boards (IRBs) related to LGBTQ research.

“The need for further research within LGBTQ communities is well established, especially for vulnerable populations such as LGBTQ-identified youth and older adults,” wrote the authors of a resolution presented by the AMA Medical Student Section at the most recent AMA Interim Meeting.

Because of inadequate legal protection for LGBTQ populations, the authors wrote, disclosure of research participants’ sexual and gender minority status through collection of sexual orientation and gender identity (SOGI) data or LGBTQ research affiliation can negatively impact their livelihoods.

The AMA adopted the resolution’s recommendations as policy supporting the creation of a model training for IRBs to use or modify for LGBTQ research.

The resolution’s authors noted that several prominent LGBTQ health organizations do not have a standardized training module to protect SOGI data and LGBTQ patient identity in research processes and suggested ways to protect patients.

A study cited by the resolution’s authors, “Guidance and Ethical Considerations for Undertaking Transgender Health Research and Institutional Review Boards Adjudicating this Research,”

was published in the journal *Transgender Health*.

Among other factors, the article outlines the following issues that have caused research involving transgender people specifically and LGBTQ patients generally to be inadequate, inaccurate, unsafe or unethical.

IRB as research impediment

“Although some caution is justified, too much may result in obstructive processes, lengthen the time taken to approve IRB applications, discourage research into complex topics and cause researchers to avoid controversial issues and innovative research,” the *Transgender Health* article says.

The AMA is dedicated to creating an inclusive environment for the LGBTQ community and ensuring they get the care they need. Get the latest LGBTQ health care news and policy coverage on the AMA

Negligent data collection

Research into LGBTQ populations may involve the collection of sensitive data that could put participants at serious personal risk, since, for some people, basic demographic information is enough to identify them.

“Anonymity can be protected in a variety of fashions, such as [by] employing identification codes, retaining data in secure storage and/or letting participants create and remember their own unique identifiers,” the authors added.

Spotty application of informed consent

Truly informed consent must be given without coercion or undue influence, says the *Transgender Health* article.

Yet “it is not clear whether informed consent is universally or consistently applied in the field of transgender health care research, particularly when this research originates in health care settings that are also the only available source of transitional services,” the *Transgender Health* article says.

Find out how the AMA has stood up for LGBTQ rights in the Supreme Court.

Historical misunderstanding, mistreatment

Health research and practice has not always been sympathetic to transgender participants and the larger community, wrote the authors of the *Transgender Health* article, adding that research “continues to tend toward representing TGGD [transgender and gender diverse] people as homogenous and lacking diversity in areas such as, but not limited to, ethnicity, gender identity and sexuality.”

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Lack of accounting for intersectionality

Intersectional theory holds that people experience particular challenges at the intersection of multiple axes of oppression.

“Unfortunately, though intersectionality is frequently discussed within social sciences and humanities transgender studies scholarship, except in some Western contexts where research is explicitly undertaken with TGGD [transgender and gender diverse] people of color, it is rarely present in the literature on transgender health,” the authors wrote.

Find out more about intersectionality and how patients’ multiple identities can affect health outcomes.

Language that stigmatizes

Some terminology may degrade the efficacy of studies and the community’s trust.

“IRBs should be aware, in scrutinizing proposals, that linguistic choices may both support and oppose TGGD stigma. Language that unnecessarily pathologizes or passes moral judgment can cause harm to participants both during the research process and on publication of findings,” wrote the authors of the *Transgender Health* article, noting that the best way to ensure the use of appropriate language is to involve community stakeholders.

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