

## A call for the urgent and definitive inclusion of gender identity and sexual orientation data in the Brazilian health information systems: what can we learn from the monkeypox outbreak?

Daniel Canavese (<https://orcid.org/0000-0003-0110-5739>)<sup>1,2</sup>  
Maurício Polidoro (<https://orcid.org/0000-0002-1881-1915>)<sup>2,3</sup>  
Marcos Claudio Signorelli (<https://orcid.org/0000-0003-0677-0121>)<sup>2,4</sup>  
Rodrigo Otávio Moretti-Pires (<https://orcid.org/0000-0002-6372-0000>)<sup>2,5</sup>  
Richard Parker (<http://orcid.org/0000-0003-3796-0198>)<sup>6,7,8</sup>  
Veriano Terto Jr. (<http://orcid.org/0000-0002-8914-8241>)<sup>6</sup>

**Abstract** *In this document, we present to the scientific community a proposal on how to deal with the challenge imposed on surveillance and health actions in Brazil regarding monkeypox, including points and directions that have the potential to support learning and enable advances in the current scenario.*

**Key words** *Monkeypox, LGBTQ people, Public health surveillance, Health information systems*

<sup>1</sup> Departamento de Saúde Coletiva, Universidade Federal do Rio Grande do Sul. R. São Manoel, 963, Rio Branco. 90620-110 Porto Alegre RS Brasil.

[daniel.canavese@gmail.com](mailto:daniel.canavese@gmail.com)

<sup>2</sup> GT de Saúde da População LGBTI+, Associação Brasileira de Saúde Coletiva. Rio de Janeiro RJ Brasil.

<sup>3</sup> Instituto Federal do Rio Grande do Sul. Porto Alegre RS Brasil.

<sup>4</sup> Departamento de Saúde Coletiva, Universidade Federal do Paraná. Curitiba PR Brasil.

<sup>5</sup> Departamento de Saúde Pública, Universidade Federal de Santa Catarina. Florianópolis SC Brasil.

<sup>6</sup> ABIA – Associação Brasileira Interdisciplinar de AIDS. Rio de Janeiro RJ Brasil.

<sup>7</sup> Laboratório Interdisciplinar de Direitos Humanos e Saúde, Instituto de Estudos em Saúde Coletiva, Universidade Federal do Rio de Janeiro. Rio de Janeiro RJ Brasil.

<sup>8</sup> Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University. New York NY EUA.

On July 21<sup>st</sup>, 2022, the International Health Regulations (2005) (IHR) Emergency Committee of the World Health Organization (WHO) met to deliberate on monkeypox. With no consensus among the IHR committee, on July 23<sup>rd</sup>, 2022, the WHO Director-General finally declared it a Public Health Emergency of International Concern.

From May 7<sup>th</sup> to May 25<sup>th</sup>, 2022, 86 monkeypox cases were recorded in the UK, 66 of which involved people who were gay, bisexual, and men who have sex with men (MSM)<sup>1</sup>. Another more recent and comprehensive study encompassing data from 16 countries revealed that out of the 528 monkeypox cases analyzed, 98% of people who were gay, bisexual, and MSM<sup>2</sup>. Based on the profile identified by these studies, temporary recommendations included the need to raise awareness about the disease in specific groups, e.g., men who have sex with men (MSM), gay and bisexual men, transgender people, sex workers, and people with multiple partners<sup>3</sup>.

However, the way how information has been dealt with has raised major concerns for us as researchers of the health of lesbian, gay, bisexual, *travesti*, transexual, transgender, intersex, and other sexual and gender minorities (LGBTI+) population.

It is difficult not to remember the onset of the HIV/AIDS epidemic in the early 1980s, when the first cases were registered in the LGBTI+ community, leading to major stigma for this group, as seen by the names the disease came to be known as at the time, i.e., “gay plague” or “gay cancer”<sup>4-6</sup>. One of the most pressing issues is not to let this terrible chapter in the history of world public health be repeated in the case of monkeypox since prejudice, stigma, and discrimination are still felt by the entire community to this today<sup>7</sup>. Like HIV/AIDS, monkeypox is not restricted solely to the LGBTI+ population, and can infect people of any sexual orientation and/or gender identity.

We have followed the latest WHO recommendations and studies from the Brazilian scientific community<sup>8</sup>. In Brazil, the first case was registered on June 8<sup>th</sup>, 2022. According to the Epidemiological Bulletin 18<sup>9</sup>, as of August 5<sup>th</sup>, 2022, there were 2,004 confirmed and 1,962 suspected cases.

The Ministry of Health issued a technical note 46/2022 – CGPAM/DSMI/SAPS<sup>10</sup>, mentioning that the cases were mainly in men who had intimate contact with multiple partners. Regarding the vaccination guidelines, the Ministry of Health reiterated that initiatives to vaccinate

the mass population were not recommended due to the shortage of doses. However, the same document included a note that, in the United States, vaccination is recommended for male homosexuals and bisexuals who live in areas with a broader spread of the virus and who fit the criteria for being more vulnerable to infection.

Regarding the challenge imposed on epidemiological monitoring and health surveillance at the Brazilian Universal Health System (SUS), four noteworthy points may enable learning and advances in the current scenario.

The first is to include the fields of gender identity and sexual orientation in the Brazilian Health Information Systems (SIS), which is yet to be established as a consensus or even a normative by the Ministry of Health<sup>11</sup>. Therefore, these fields are not uniformly present in the SIS that monitor events that are relevant to the Brazilian public health.

Second, it is essential to mention that in the individual registration form of primary care in e-SUS, information about gender identity (*travesti*, transgender woman, transgender man, or other) and sexual orientation (heterosexual, homosexual, bisexual, or other) is optional, which contributes to the incompleteness of data regarding the LGBTI+ population.

Third, it should be noted that, since 2014, the notification form of interpersonal and/or self-inflicted violence of the Notifiable Diseases Information System (SINAN) started to include fields for gender identity (*travesti*, transgender woman, transgender man, does not apply, and ignored) and sexual orientation (heterosexual, homosexual, bisexual, does not apply, and ignored). These fields are not included in other SINAN disease investigation and notification forms.

The fourth point is the lack of gender identity and sexual orientation in SINAN for monitoring HIV/AIDS. The notification form collects data of men who have sex with men (MSM) and women who have sex with women (WSW).

This lack of standardization in gathering information about gender identity and sexual orientation becomes more pressing amidst a recent survey that reported a diversity of more than fifty nationally-based health information systems<sup>12</sup>. Disintegration persists among all these, but the most worrisome cases are the systems related to e-SUS, health surveillance, and care for people living with HIV/AIDS and hepatitis<sup>13</sup>.

The National Monkeypox Contingency Plan<sup>14</sup> from the Public Health Emergency Operations Center of the Ministry of Health highlighted that

the notification of suspected, confirmed, and probable cases must be immediate. That encompassed a nationwide recommendation of using a REDCap instrument until the notification/investigation form arrived.

In the latest version of the REDCap available on July 29<sup>th</sup>, 2022, the fields for gender identity (trans-woman, cis-woman, *travesti*, trans-man, cis-man, non-binary) and sexual orientation (heterosexual, homosexual, bisexual, pansexual, ignored, other) became mandatory. The fields for men who have sex with men (yes, no, ignored), other sexual behaviors (sex with men, sex with women, sex with men and women), and multiple partners (yes, no, ignored) were also included.

That resulted in an increase in the number of fields and response options, an absence of standardization, and a persistent lack of conceptual definitions regarding gender identity and sexual orientation in the SIS. Amidst the uncertainty caused by the monkeypox outbreak in Brazil and the daily challenges faced by health services when filling in information about gender identity and sexual orientation (in the systems that already make this a possibility), there are also the dangers of misinformation and the perpetuation of stigmas related to the LGBTI+ population, which are still obstacles for this group to have access to health services.

Given this topic's urgency and complexity, critical insights from the Public Health scientific community might prove helpful. It is essential to recognize the lessons learned and take practical actions to end health disparities, promote health policies in compliance with the principles of equity, and advance the implementation of the National LGBT Comprehensive Health Policy.

As an initial synthesis, we share with the scientific community, health managers, and civil society the lessons learned and the urgent matters that must be addressed when facing monkeypox:

1. Definitive implementation of the fields of gender identity and sexual orientation in the SIS as an emergency due to the current monkeypox outbreak;

2. Institution of regulations by the Ministry of Health, such as Ordinance 344 of February 1<sup>st</sup>, 2017, for the standardization of how to fill in the fields of gender identity and sexual orientation, including conceptual definitions;

3. Capacity building and training of health professionals and the population regarding the relevance of data and how to deal with the self-identification of race/color and ethnicity, gender identity, and sexual orientation;

4. Monitoring if self-identification fields, e.g., race/color, gender identity, and sexual orientation, have been filled in SIS, thereby improving the completeness and quality of the data;

5. Using gender identity and sexual orientation data in health analyses and making the databases open and public for consultation by the scientific community;

6. Disclosing data on monkeypox in epidemiological bulletins based on race/color and ethnicity, gender identity, and sexual orientation;

7. Developing health campaigns and materials with relevant information for specific issues and groups, e.g., LGBTI+ people, with special attention to the topics of stigma and discrimination;

8. Developing communication strategies focused on monkeypox that do not promote stigma, discrimination, and misinformation;

9. Adopting immediate health actions aimed at the most vulnerable groups in the face of monkeypox, including testing, vaccination, clinical care, and guidance. Here, it is also worth mentioning the need for specific measures for people living with HIV based on ongoing initiatives<sup>15</sup>;

10. Investment and strengthening of scientific production in health that incorporates analyses from an intersectional perspective and is based on data regarding race/color and ethnicity, gender identity, and sexual orientation.

## Collaborations

D Canavese and M Polidoro designed the document. All authors had equal participation in the writing and review of the article.

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