

Letter to the Editor

Modernizing Gender, Sex, and Sexual Orientation Data Through Engagement and Education

Lia Ginaldi*, MD, Prof Dr; Massimo De Martinis*, MD, Prof Dr

Department of Life, Health and Environmental Sciences, University of L'Aquila, L'Aquila, Italy

* all authors contributed equally

Corresponding Author:

Massimo De Martinis, MD, Prof Dr
Department of Life, Health and Environmental Sciences
University of L'Aquila
Piazzale Salvatore Tommasi n.1
L'Aquila, 67100
Italy
Phone: 39 0861 429548
Fax: 39 0861 211395
Email: demartinis@cc.univaq.it

Related Articles:

Comment on: <http://www.jmir.org/2023/1/e46773/>

Comment in: <http://mhealth.jmir.org/2023/1/e52286/>

(*J Med Internet Res* 2023;25:e51632) doi: [10.2196/51632](https://doi.org/10.2196/51632)

KEYWORDS

data sharing; digital health systems; digital health; gender, sex, and sexual orientation; electronic health records; GSSO; health information standards; LGBT health; LGBT; policy; LGBTQIA+; gender medicine

We were pleased to read the article by Queen et al [1], which reports a sensitive, precise, and effective discussion on the need for and how to modernize the terminology of gender, sex, and sexual orientation (GSSO) in the digital health system. The authors warn us about the risks of inaccurate and potentially harmful clinical care due to the inability of most digital health systems to record, store, and manage GSSO data. Sex and gender minorities (SGMs) are emerging as relevant components of our society and are increasing numerically, but they unfortunately face health and health care inequities. Current population data remain oblivious to an accurate accounting of SGMs [2], but there has been a focus on this topic for a long time, numerous proposals have been made to overcome these shortcomings, and scientific production in this area has grown exponentially in recent years. The lack of reliable and specific data is one of the fundamental issues to focus efforts on to have reliable and valid resources to conduct studies that are specific to these population groups and help overcome health disparities. To inform treatments and policies for interventions and identify health inequities, we need larger and more diverse SGM samples that integrate multiple data sources.

Modernizing and expanding GSSO information practices may inform the development and equitable implementation of prevention and treatment guidelines for the growing lesbian, gay, bisexual, transgender, queer/questioning, and intersex (LGBTQI+) population. However, to date, a seemingly trivial

issue that is fundamental and requires attention and commitment is education on inclusivity and respect for diversity. For example, numerous studies have confirmed that education on the specific health issues of LGBTQI+ populations is lacking in health curricula, and health professionals often report their shortcomings in this area. Knowledge and sensitivity to LGBTQI+ issues are fundamental in the global population and especially in each person in care pathways. If knowledge, the ability to listen and welcome, and sensitivity in data collection are lacking, any other progress in other more technical aspects is likely to be thwarted [3].

In summary, achieving equitable progress in clinical care requires addressing global disparities, which requires a multidisciplinary approach, improving the collection of health data such as GSSO information, and reducing social taboos through education [4]. Everyone, operators and users, must be given the tools to understand, be sensitive, feel involved, and participate appropriately in this process. Collaborative partnerships are the basis for responding to complex disparities in communities; positive outcomes and the codevelopment of systems and priorities can only be achieved with strong collaborative relationships. Furthermore, health equity programs, comprehensive insurance policies, gender-inclusive and gender-specific research, targeted screening, and personalized treatment programs, together with specific SGM engagement

strategies [5], are crucial to eliminating health care disparities for the LGBTQI+ community.

Conflicts of Interest

None declared.

References

1. Queen R, Courtney KL, Lau F, Davison K, Devor A, Antonio MG. What's next for modernizing gender, sex, and sexual orientation terminology in digital health systems? Viewpoint on research and implementation priorities. *J Med Internet Res* 2023 Jul 25;25:e46773 [FREE Full text] [doi: [10.2196/46773](https://doi.org/10.2196/46773)] [Medline: [37490327](https://pubmed.ncbi.nlm.nih.gov/37490327/)]
2. Streed CG, Lett E, Restar A. Assessing the health status of sexual and gender minority adults: what we can learn when we include all of us. *JAMA Netw Open* 2023 Jul 03;6(7):e2324948 [FREE Full text] [doi: [10.1001/jamanetworkopen.2023.24948](https://doi.org/10.1001/jamanetworkopen.2023.24948)] [Medline: [37523189](https://pubmed.ncbi.nlm.nih.gov/37523189/)]
3. Tran NK, Lunn MR, Schulkey CE, Tesfaye S, Nambiar S, Chatterjee S, et al. Prevalence of 12 common health conditions in sexual and gender minority participants in the all of us research program. *JAMA Netw Open* 2023 Jul 03;6(7):e2324969 [FREE Full text] [doi: [10.1001/jamanetworkopen.2023.24969](https://doi.org/10.1001/jamanetworkopen.2023.24969)] [Medline: [37523187](https://pubmed.ncbi.nlm.nih.gov/37523187/)]
4. Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex, and sexual orientation documentation in electronic health records. *J Am Med Inform Assoc* 2020 Nov 01;27(11):1774-1783 [FREE Full text] [doi: [10.1093/jamia/ocaa158](https://doi.org/10.1093/jamia/ocaa158)] [Medline: [32935124](https://pubmed.ncbi.nlm.nih.gov/32935124/)]
5. Sirifo MM, Magnanini LM, Ginaldi L, De Martinis M. Overcoming LGBTQI+ disparities in cardio-oncology: a call to action. *JACC CardioOncol* 2023 Apr;5(2):267-270 [FREE Full text] [doi: [10.1016/j.jacc.2022.11.017](https://doi.org/10.1016/j.jacc.2022.11.017)] [Medline: [37144105](https://pubmed.ncbi.nlm.nih.gov/37144105/)]

Abbreviations

GSSO: gender, sex, and sexual orientation

LGBTQI+: lesbian, gay, bisexual, transgender, queer/questioning, and intersex

SGM: sex and gender minority

Edited by T Leung; this is a non-peer-reviewed article. Submitted 06.08.23; accepted 27.10.23; published 15.11.23.

Please cite as:

Ginaldi L, De Martinis M

Modernizing Gender, Sex, and Sexual Orientation Data Through Engagement and Education

J Med Internet Res 2023;25:e51632

URL: <https://www.jmir.org/2023/1/e51632>

doi: [10.2196/51632](https://doi.org/10.2196/51632)

PMID:

©Lia Ginaldi, Massimo De Martinis. Originally published in the Journal of Medical Internet Research (<https://www.jmir.org>), 15.11.2023. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. The complete bibliographic information, a link to the original publication on <https://www.jmir.org/>, as well as this copyright and license information must be included.