

# Including sexual orientation and gender identity data to advance nephrology care

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Understanding of the barriers to adequate health care experienced by sexual and gender minority (SGM) people cannot be achieved in the absence of robust and appropriate data. The inclusion of SGM populations in health research and the collection of sexual orientation and gender identity data in research and routine clinical practice is therefore essential to understanding the unique needs of these populations and addressing inequities in health outcomes.

Sexual and gender minority (SGM) populations, including lesbian, gay, bisexual, transgender and queer (LGBTQ+) people, face numerous barriers and inequities in access to health care and health outcomes<sup>1</sup>. However, our ability to understand the reasons underlying these barriers and inequities, as well as their consequences, is hindered by an absence of population-specific data. To overcome this shortfall in the availability of robust and appropriate data, in 2016 the National Institute on Minority Health and Health Disparities designated SGM populations as a health disparity population for research purposes<sup>2</sup>. Although this designation opened funding opportunities for research into issues related to SGM health, it did not provide guidance on how best to achieve it, particularly with regard to which data elements are essential and which outcomes may be of immediate interest. Consequently, despite this overall push for more data, information on kidney-specific health outcomes in SGM populations remains insufficient owing to the inadequate collection of sexual orientation and gender identity (SOGI) data in the majority of kidney research<sup>3</sup>. Further, clinical settings have only recently begun to incorporate SOGI data in their routine practice. The lack of appropriate research and clinical data specific to SGM populations can taint any subsequent tools derived from it. For example, clinical decision tools that rely on sex assigned at birth fall short for transgender and gender diverse (TGD) populations receiving gender-affirming hormone therapy (GAHT), as such therapy might affect parameters such as lean muscle mass that are considered in the assessment of kidney function. Hence, rigorous and robust SOGI data collection must be enacted in nephrology research and clinical practice as a matter of urgency to address disparities in health outcomes among SGM people.

Nephrologists and kidney researchers cannot assess or address potential barriers and inequities in health care and health outcomes until such inequities and clinical shortcomings are tracked and quantified. To accomplish meaningful changes in clinical outcomes, SOGI

data must be collected as part of research and clinical standards. At minimum, SOGI data include information on sexual orientation, sex assigned at birth, gender identity and intersex status. Additional guidance on how best to include SOGI data collection, including appropriate responses based on community input, was released<sup>4</sup> by the National Academies of Sciences, Engineering, and Medicine in 2020. However, even in the absence of nephrology-specific data, nephrologists can begin to anticipate the unique needs of SGM people by acknowledging the known inequities in access to care and disease burden, and SGM-specific health concerns that are likely to affect the kidney health of members of these communities. Specifically, the kidney health of SGM people is likely to be affected by barriers in access to consistent, high-quality primary care, including access to disease screening (for example, for hypertension and diabetes), and may also be affected by additional factors, such as the use of substances including tobacco and alcohol and the use of prescription drugs including GAHT and HIV pre-exposure prophylaxis.

## “SOGI data must be collected as part of research and clinical standards”

One in three adults in the US general population (that is, over 80 million people) are at risk of kidney disease due to the presence of underlying conditions, including diabetes and hypertension. Early detection of these risk factors can slow or prevent the progression of kidney disease, particularly with the emergence of therapies such as SGLT2 inhibitors. However, inequity in access to primary care for SGM people may limit their access to screening for these predisposing conditions and increase their risk of subsequent kidney disease. The barriers to primary care for SGM individuals are multifactorial and include inadequate training for health-care providers in the provision of affirming and inclusive care for SGM people as well as distrust of medical professionals due to previous negative experiences or fear of judgment from their providers. Compounding these barriers to the early detection of risk factors, some SGM populations are also at increased risk of diabetes and hypertension through various physiological pathways linked to minority stressors<sup>5</sup>.

Additional concerns arise with the use of medications that are more commonly prescribed to SGM populations. Potential interactions between medications, dosing for decreased kidney function, and the potential for nephrotoxicity must be considered and assessed. Certain forms of HIV pre-exposure prophylaxis (for example, emtricitabine-tenofovir disoproxil) can be nephrotoxic or induce metabolic adverse effects that can predispose to or exacerbate existing kidney disease. Patients with existing kidney disease, as well as kidney transplant recipients, are often prescribed immunosuppressive therapies, including steroids and calcineurin inhibitors, and are therefore at increased

risk of virally driven cancers. However, data on the rates of human papilloma virus (HPV)-driven cancer – including anal cancer, which has an increased incidence among gay, bisexual, and other men who have sex with men<sup>6</sup> – among patients on immunosuppressive therapy are limited. Moreover, no clear guidance on screening practices exists, and these therefore represent an area that requires further study<sup>7</sup>. Furthermore, as with the COVID-19 vaccine, patients who are on immunosuppressive therapies may not mount a full immunologic response to HPV vaccination; thus, additional insights into the efficacy of such preventative strategies on the risk of disease is important to develop future screening guidelines for this population<sup>8</sup>.

For patients who are TGD, further study is needed to understand the impact of GAHT on the kidney and on estimates of kidney function, which currently are calculated on the basis of sex assigned at birth. As with removal of the race coefficient, continued consideration and research is needed into the limitations of available equations for estimating glomerular filtration rate that rely on binary sex categories and may need re-evaluation in TGD people. Use of the cystatin C calculation for estimating glomerular filtration rate may have theoretical advantages over the use of creatinine-based equations for TGD people who are on GAHT, as it will not be affected by changes in muscle mass; however, data specific to TGD populations that support this hypothesis are lacking<sup>9</sup>.

In addition to these specific clinical scenarios in which limitations in research data affect clinical care, the failure to collect SOGI data in clinical settings also affects the care received by SGM populations. Unfortunately, most patients with chronic kidney disease are unaware of their disease until late in its progression, at which point they may already need dialysis. Caring for patients with chronic kidney disease or kidney failure requires an understanding of their psychosocial environment, as the support they receive and the environment in which they live can affect their access to dialysis modalities, eligibility for transplant wait-listing, and a variety of other factors that can influence patient outcomes and well-being. Full understanding of a patient's SGM identity is critical to inform a holistic view of this psychosocial environment. Of note, SGM populations are – like any other population – diverse. Many individuals who identify as SGM face unique needs and challenges beyond those associated with their SGM status, for example, as a consequence of socioeconomic status, race or ethnicity, geographic location, disability or other marginalized identities. Consistent and robust SOGI data collection, combined with research into the health inequities faced by such multiply marginalized patient populations, is needed to address and correct them.

Ultimately, the dearth of appropriate SOGI data collection and the absence of SGM people in clinical research forecloses opportunities to understand the unique needs of these populations in clinical care and limits the functionality of any tools developed from research data. The absence of adequate data erases SGM people and their needs from the medical literature by failing to adequately capture the impact of SGM status on health care and health outcomes. Moreover, this knowledge gap precludes the opportunity to assess the various social, environmental, and clinical factors that intersect with SGM identities.

## “The absence of adequate data erases SGM people and their needs from the medical literature”

Although it may seem novel to consider SGM populations in nephrology, the collection of SOGI data is not a new clinical or research practice. Guidance from national leaders in SGM care and research have provided training and resources for decades to ensure that SGM patients are identified in the electronic health record and that SGM research participants are visible in the collected data<sup>3,10</sup>. The tools to assess and address the kidney health of patients are available. What remains to be seen is whether necessary steps will be taken by the nephrology community to ensure that SGM populations are not overlooked.

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### Competing interests

The authors declare no competing interests.