



Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-user Practices

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Key words: *electronic health records, MeSH terms: statistics and numerical data, transgender persons*

A transgender person may have a preferred name, preferred pronoun, and gender identity, any of which can differ from what is listed in their legal documentation. In addition to negatively impacting patient experiences (e.g., being called by a birth name rather than one's gender-congruent preferred name in a crowded waiting room), incomplete or inconsistent documentation of this information in an electronic medical record (EMR) can impact care (Kosenko, Rintamaki, Raney, & Maness, 2013; Melendez & Pinto, 2009). For example, a patient listed as male in the EMR may have a cervix and require related screening reminders and documentation of a physical examination (Deutsch et al., 2013; Melendez & Pinto, 2009; Mizock & Lewis, 2008; National Gay and Lesbian Task Force, 2011). Some EMR systems, as well as provider uses of such systems, fail outright to identify transgender patients; the resulting systematic erasure leads to reduced funding allocations as well as impaired quality improvement and research efforts (Bauer et al., 2009).

Collecting gender identity data has received support from a multitude of entities and reports including the Institute of Medicine (National Research Council, 2013), Healthy People 2020 (U.S. Department of Health and Human Services, 2010), the Affordable Care Act (Center for American Progress, 2012), the Institute of Medicine (2011), and the Joint Commission (2011). *Meaningful Use* refers to incen-

tive programs implemented by the Centers for Medicare and Medicaid Services. These programs provide financial incentives for the meaningful use of certified electronic health record technology to improve patient care. The programs are staged in three steps with increasing requirements for participation (Centers for Medicare and Medicaid Services, n.d.). Gender identity was not included in Meaningful Use Stage 2 as the Office of the National Coordinator for Health Information Technology felt there was insufficient evidence to support a best practice for doing so; Stage 3 is currently under review (Cahill & Makadon, 2014; Carroll, 2012). While inclusion in Meaningful Use guidelines will be an essential step toward more universal adaptation of this process, recommendations based on rigorous and validating research to guide such an inclusion are lacking.

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That said, given the limited funding opportunities for such research as well as a paucity of active researchers in the field, it is conceivable that such studies (and researchers to conduct them) may take years to materialize. In the interim, it would seem unfortunate to, as one recent paper on the subject opined, “let the perfect be the enemy of the good” (Cahill & Makadon, 2014, p. 39) and miss an opportunity to integrate these parameters into Meaningful Use as well as the burgeoning field of EMR products.

Several recent publications have begun to explore the collection of gender identity and related information (i.e., preferred name and pronoun) from transgender patients, as well as how this information is documented using EMRs. Initial best practice recommendations from the World Professional Association for Transgender Health (WPATH) were recently published; however, little is known about current clinician end-user implementation and use patterns (Cahill & Makadon, 2014; Deutsch et al., 2013). Anecdotal experience suggests that data are collected in an inconsistent fashion and stored in inconsistent locations in the record across platforms and institutions, adding further mystery and confusion to what is already a challenging topic for some providers and clinic staff to understand.

Many experts have begun to recommend the use of a two-step process for the collection of gender identity information (Cahill & Makadon, 2014; Deutsch et al., 2013). This method involves first querying gender identity and then birth sex. Transgender persons can be identified as those whose gender identity and birth sex are discordant. One study of university students found that roughly twice as many transgender persons were identified using a two-step method as compared to a one-step method, in which a single question was used querying sex/gender and allowing responses of *male*, *female*, and *transgender* (Tate, Ledbetter, & Youssef, 2013). Although some have expressed concern that routine collection of gender identity information could place patients at risk of discrimination, researchers at the Fenway Institute have found that “patients seem as willing to provide [gender identity] information as financial information” (Cahill & Makadon, 2014, p. 37). Some agencies such as the [Health Resources and Services Administration \(2010\)](#) have not yet adopted the two-step method and therefore may

report statistics that do not accurately represent the impact of HIV in the transgender community. Given that transgender women in the United States have been shown to have an HIV seroprevalence of 21.7% (odds ratio 34.2), insuring widespread accurate and consistent recording of gender identity data is essential to inform the development and support of HIV-related services specific to the transgender community (Baral et al., 2013).

Little evidence exists to guide the actual mechanics of gender identity data collection. Such information may be collected in various ways: in face-to-face questioning by clinic staff or providers, via a pen-and-paper form to be entered into the EMR, or by self-report via electronic kiosk or online patient portal. Research has suggested that self-reporting via an electronic system may yield more accurate information. Participants in a mixed-methods study of young adults presenting to community clinics reported being more honest and feeling less judged when using a tablet-based touch-screen interface to report sexual histories than with a face-to-face interview by a provider; such a method was also reported to be simpler to use and “fun” (Mackenzie et al., 2007).

Our study had two primary aims: (a) to determine current clinician end-user practices for the documentation of gender identity-related information within EMRs (preferred name, preferred pronoun, birth-assigned sex, and gender identity); and (b) to determine the mechanics with which such information is collected from patients. Quantifying current clinician practices will provide an assessment of need for guidance in this area; inform efforts to further develop, test, standardize, implement, and disseminate best practices such as the two-step method and the WPATH EMR Working Group Recommendations (Deutsch et al., 2013); as well as illuminate areas for future study such as actual collection mechanics.

Materials and Methods

Study design and methods were reviewed and approved by the Committee on Human Research at the University of California – San Francisco. A survey was electronically distributed in May 2013 to a convenience sample of subscribers to the WPATH

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