Future of Sexual Orientation/Gender Identity (SO/GI) Healthcare Data

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The LGBT patient population have identification and documentation needs that are not being addressed in today's mainstream healthcare workflows. Capturing sexual orientation and gender identity (SO/GI) is a relatively new concept and the need for this standardized, private, and secure data capture is becoming even more important. To care for all patient subpopulations regardless of SO/GI, race, or ethnicity, healthcare organizations need to emphasize more personalized and proactive healthcare for all patients.

The March 2016 Program Assistance Letter from HRSA created a sense of urgency among the agency's 1,375 federally qualified health centers to find ways to reduce health disparities and provide culturally competent care for the LGBT patients in their healthcare footprint (24 million patients served in the US). It requires SO/GI data to be collected in the Uniform Data System and establishes guidelines to provide better, more efficient, and higher quality care for the LGBT patient population.

The 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Program Modifications, published March 30, 2015, includes guidance on recording, changing, and accessing structured SO/GI data. It is important to note that while this enables users to collect SO/GI data points, doing so is not a documentation requirement and the new data fields are not currently stored in most Master Patient Index (MPI) and Enterprise Master Patient Indexes (EMPIs).

Reverse engineering will be needed to accommodate new workflows. For those HIM professionals and clinician partners who are ahead of the curve and are addressing data collection with new questionnaires and workflows in their facilities, the intake of SO/GI data is being addressed during the clinical visit with a trusted clinical provider. This is the preferred method over collecting this data during the front-end registration due to the sensitive nature and approach. But for the data to be interoperable it must make its way back to the MPI and EMPI alike. The lasting impact of this data will likely change the face of our legal health record and have a positive impact on LGBT patients' clinical experiences and care outcomes. Our ultimate goal as an industry should be to collect accurate and reliable SO/GI data with integration(s) into the EHR. To get there, much work needs to be done.

It is well known that MPIs are fraught with patient identity errors, with a mid-sized healthcare facility having an average duplicate error rate of eight to 14 percent. Adding the capture of SO/GI data elements must be carefully constructed, while keeping standards development organizations (SDOs) and technology vendors in mind. MPIs/EMPIs will need to accommodate these new fields to ensure exchange and interoperability. Today, most MPIs capture "Male," "Female," and "Unknown" in the EHR under the "gender" or "sex" category and assumes gender and sex are synonymous. Separate field values for both "gender" and "sex" should be considered as a future system enhancement along with standardized data to populate each field value. The distinction between gender and sex should be well defined to limit confusion.

To reduce the risk of inaccurately documenting patient data, HRSA's Program Assistance Letter outlines key data elements patients can select to accurately self-identify. These include selections that extend beyond Male and Female to include options such as "Transgender Male/Male-to-Female" and "Transgender Female/Male-to-Female." Documentation of patients' aliases, preferred names, and pronouns as well as the progress of their transitions are vital to ensuring proactive and sensitive treatment of the patient.

A significant area of concern for transgender patients includes identifying with preferred names and pronouns that differ from those listed on health insurance policies, birth certificates, and driver's licenses. These documents might also change throughout the stages of their transition, which reinforces the need for concurrent updates. Collecting this needed information will help prevent an increased rate of occurrence in delayed treatment(s), patient dissatisfaction, and possible errors in treatment.

A strong data and information governance foundation will support these future proposed changes in our systems and processes with a focus on caring for all patients.

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