



BEFORE THE UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications)..... RIN 0991-AB93

Medicare and Medicaid Programs; Electronic Health Record Incentive Program – Stage 3)..... RIN 0938-AS26

COMMENTS OF WHITMAN-WALKER HEALTH ON PROPOSED COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA IN CERTIFIED HEALTH IT SYSTEMS, AND INCORPORATION OF THIS INFORMATION IN MEANINGFUL USE

Whitman-Walker Health (WWH) offers these comments on the proposed collection of sexual orientation and gender identity (SOGI) data on patients set out in the Notice of Proposed Rulemaking in RIN 0991-AB93. We applaud the Department’s proposal to require collection of this data for certified health IT systems, and propose several changes to the questions asked, and the options for responses, to improve the accuracy of the information collected and its usefulness for providing competent health care and further public health efforts to identify and address health disparities. In addition, because of the importance of sexual orientation and gender identity for patient care, we urge that the requirements for Meaningful Use set out in the Notice of Proposed Rulemaking in RIN 0938-AS26 be supplemented to require the collection of SOGI data, and demonstration of how that data is used to deliver health care.

Interest and Expertise of Whitman-Walker Health

WWH is a Federally Qualified Health Center located in Washington, DC. Our mission is to be the highest quality, culturally competent community health center serving greater Washington’s diverse urban community, with a special focus on the lesbian, gay, bisexual and transgender (LGBT)

ELIZABETH TAYLOR MEDICAL CENTER ADMINISTRATION 1701 14th Street, NW Washington, DC 20009 202.797.3500	MAX ROBINSON CENTER 2301 M I. King, Jr. Avenue, SE Washington, DC 20020 202.678.8877	CALL CENTER 202.745.7000 www.whitman-walker.org
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community, persons living with HIV, and other individuals and families who face barriers to accessing care. We offer primary medical and specialty HIV and transgender care; dental care; mental health and addictions counseling and treatment; HIV education, prevention, and testing services; other community health services; legal services; and medical adherence care management.

For more than three decades, WWH has been a nationally recognized leader in HIV treatment and prevention, and we have been committed to advancing LGBT health and wellness for almost 40 years. In calendar year 2014, we provided health services to more than 14,700 individuals. Approximately one-half of those individuals identified as gay, lesbian or bisexual, and approximately 13% of medical patients, and 6% of all persons receiving health services, identified as transgender. Our interest in recording and maintaining consistent and accurate data on patient sexual orientation and gender identity is grounded in our experience as direct health care providers and as an advocate for sound public health policies. Reducing health disparities among LGBT individuals and communities relies on collecting standardized SOGI data collection among patients and using it to inform clinical care. SOGI data collection and use is also critically important to removing the invisibility of these individuals in many clinical settings and public health initiatives.

Comments on SOGI Data Collection for Health IT Certification – RIN 0991–AB93

The proposed rule introduces new certification criteria for health IT, including a “social, psychological, and behavioral data” certification criterion to support efforts to reduce health disparities and improve health care (80 Fed. Reg. at 16826).¹ Specifically, this criterion proposes that health IT have the capacity to record, change, and access a range of “social, psychological and behavioral” information on patients that is related to health. The proposed domains for sexual orientation and gender identity are included in this criterion (*id.* at 16829).

¹ All references are to the versions of the Notices of Proposed Rulemaking that were published in the Federal Register on March 30, 2015.

The Notice proposes several questions (80 Fed. Reg. at 16829) and invites comments. Our responses are set out below.

Have the appropriate measures been included for the listed social, psychological, and behavioral data?

Certified health IT systems should accurately and consistently record patient sexual orientation and gender identity. Although current data on sexual orientation and gender identity is inadequate in many respects, it is clear that LGBT people suffer from a wide range of health challenges and disparities – as highlighted, for instance, in the Department’s *Healthy People 2020*² and the Institute of Medicine’s *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (2011).³ Standardized and widespread collection of SOGI data in electronic health records is essential to identifying specific patient health care needs, so that competent care can be provided. Such data are also essential to developing a thorough, comprehensive understanding of LGBT health disparities at the population level, so that those disparities can be addressed.

Should there be standardized questions associated with the collection of sexual orientation and gender identity data? If so, what vocabulary standard is best suited for coding standardized questions?

Are the proposed standard sexual orientation and gender identity terms, which are based on Systematized Nomenclature of Medicine codes, appropriate?

We agree that there should be standardized questions associated with the collection of SOGI data. Sexual orientation and gender identity are highly sensitive and frequently misunderstood, by providers and patients alike. In order to ensure consistency and accuracy of SOGI data, health systems and providers who collect the data through registration or intake forms (whether printed or electronic) should all pose the same questions. Where information is collected through in-person

² <http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>.

³ Washington, DC: National Academies Press; 2011, available at <https://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>.

interview rather than through a form, or where the patient is confused by the form, standardized questions may function as additional guidance for providers who are not personally comfortable with the topic or who are not fully informed or competent to have conversations with their patients about these matters. We propose such standardized questions below. We also submit that the specific SOGI terms proposed in the Notice should be modified in order to improve accuracy and minimize confusion.

Sexual Orientation

Sexual orientation is a complex concept, encompassing attraction, behavior, and identity. Questions about sexual orientation may address any one of these components and vary depending upon the purpose of data collection or research. We propose a question for the sexual orientation data field that reflects how individuals conceptualize their own sexuality, following the methodology used in the 2013 National Health Interview Survey.⁴ Structuring the question in this manner allows individuals to respond based the various aspects of their lives that define sexual orientation for them, including behavior and attraction. As stated by the working group involved in developing the NHIS sexual orientation question delineates the utility of focusing on identity: “In the context of health, sexual identity is informative in understanding respondents’ access to health care and, subsequently, the quality of care they are provided. It is also informative in understanding risk factors such as diet, exercise, stress and smoking patterns as these factors are closely linked to community as well as self-conception.”⁵

⁴ Ward BW, Dahlhamer JM, Galinsky AM & Joestl SS., *Sexual Orientation and Health Among U.S. Adults: National Health Interview Survey, 2013*. National Health Statistics Reports; no 77: National Center for Health Statistics, Hyattsville, MD, 2014; Miller K & Ryan JM., *Design, Development and Testing of the NHIS Sexual Identity Question*, Questionnaire Design Research Laboratory, Office of Research and Methodology: National Center for Health Statistics, 2011, available at http://wwwn.cdc.gov/qbank/report/Miller_NCHS_2011_NHIS%20Sexual%20Identity.pdf.

⁵ *Design, Development and Testing of the NHIS Sexual Identity Question*, supra n.4, at 2.

We thus propose the following specific question and response options for the Sexual Orientation data field:

How do you think of yourself in terms of your sexual orientation?

Homosexual/gay/lesbian/same-gender-loving/queer

Heterosexual/straight/not gay

Bisexual

Something else/not listed

Because different individuals are comfortable with very different terms to describe their sexual identity, we recommend expanding the “Homosexual” and “Heterosexual” options proposed in the Notice in the manner set out above. We also recommend replacing the “Other”, “Unknown” and “Asked but unknown” options proposed in the Notice with “Something else/not listed,” for purposes of clarification, and to reduce the number of options so as to improve the usefulness of the data from a population perspective.

Standardized questions for oral collection of data. When sexual orientation information is collected from patients orally – for instance, in an in-person history taken by a provider, or when the patient fails to answer the question on the form or expresses confusion about the question – we recommend that the provider or other health center staff person repeat the question, and if the patient expresses confusion or discomfort with the question as posed, follow up with the following:

This question is about who you are attracted to sexually and romantically.

Are you attracted to men, or to women, or to both men and women?

Caveat: providers will need to follow up with individual patients with specific questions about their sexual behavior. Questions related to a patient’s sexual behavior are, of course, central when identifying their specific health care needs. For instance, whether an individual is at high risk of HIV or other sexually transmitted infections is determined by their specific sexual

practices and behaviors, whether they are homosexual, heterosexual or bisexual. Broad classifications based on sexual orientation, alone, are not a proxy for specific sexual behaviors, and are no substitute for respectful, careful questioning about sexual behaviors that could be relevant to a patient's health. Exploration of sexual behavior should occur during the clinical encounter with every patient, regardless of their self-identified sexual orientation.

Gender Identity

We recommend that the gender identity data field proposed in the Notice be modified in two ways: two separate data fields should be created rather than just one; and the response options should be changed.

Collection of gender information in two fields. We propose that gender identity be collected by means of two separate questions:

Current gender identity

Sex assigned at birth

This approach allows patients to provide information about their history that is likely to be relevant to their health needs, while also validating and affirming their current gender identity. This two-question approach is recommended by the University of California San Francisco's Center of Excellence.⁶

As for options for gender identity, the term "transsexual" proposed in the Notice, based on old and outdated SNOMED codes, should be changed to "transgender". The label "transsexual" is no longer widely used by transgender individuals, and many find the term to be offensive. The data fields and options for responses that we recommend are:

⁶ Sausa, LA, Sevelius J, Keatley J, Iniguez JR & Reyes M., *Policy Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care and Services*. Center of Excellence for Transgender HIV Prevention: University of California, San Francisco, 2009, available at www.transhealth.ucsf.edu.

What is your current gender identity? (Check all that apply)

Male

Female

Transgender male/Trans man

Transgender female/Trans woman

Gender queer/ non-binary

Something else/ not listed

What sex were you assigned at birth?

Male

Female

Intersex

With regard to current gender identity, we submit that our recommended language more accurately reflects current terminology and is more respectful of the diversity of the transgender community. Thus, the questions are more likely to facilitate respectful, trusting relationships of patients with providers, and the responses provided by patients are more likely to yield accurate information for population health purposes. As noted above, “transsexual” is not a label to which many transgender persons relate, and for many the term is pejorative. The terminology we propose is more accurate and respectful. “Non-binary” more accurately reflects the self-identity of some gender-nonconforming people, so we have added that term to the “gender-nonconforming” option. We also recommend replacing “Other” and “Asked but unknown” with “Something else/not listed” to simplify the choices and reduce potential confusion.

One important point is that *these recommended two gender questions need to replace the current “sex” data field* in the criteria for health IT systems. Otherwise, health records will be redundant at best, and in many cases are likely to be confusing and inaccurate.

It is also important to note that **in order to obtain an accurate report of the number of transgender patients, it will be necessary to cross-reference individual responses to both gender questions**, so as to include

all individuals who list their gender identity as transgender; and

all individuals whose answers to the sex-assigned-at-birth question and to the gender-identity question do not match.

While this is somewhat more complicated than if a single gender-related data field were used, the use of two fields – for sex assigned at birth and for gender identity – is critical to assure medically and culturally competent health care. Health care providers often will need to know not only a patient’s gender identity, but their sex assigned at birth (for instance, to know that a transgender woman may need to be screened for prostate cancer, or that a transgender man may need to be screened for cervical or ovarian cancer).

Should these measures be part of one certification criterion or separate certification criteria?

We applaud the Department for including a number of important social determinants of health in the “social, psychological, and behavioral data” certification criterion, as part of an effort to better assess health disparities. However, SOGI data elements do not belong in the “social, psychological, and behavioral data” certification criterion, as they are more closely aligned with other identity-related demographic questions.

We propose moving SOGI data elements to either its own certification criterion or as part of the “demographics” certification criterion. Sex is clearly within the demographics criterion, so the two gender-related we recommend (gender identity and sex assigned at birth) belong there. Moreover, as noted above, the two gender-related questions we propose need to replace the “sex” data field. Sexual orientation is a fundamental category of identity, and fundamental to assessing and addressing important health disparities, so it belongs with sex, race/ethnicity, age, and other fundamental demographics.

**Comments on Electronic Health Record Incentive Program, Stage 3 (Meaningful Use) –
RIN 0938–AS26**

The Notice on Stage 3 of the Medicare and Medicaid “Meaningful Use” Incentive Program fails to include sexual orientation or gender identity data collection or measures in any of the eight proposed program objectives. This oversight should be corrected in the final rules. Collection of SOGI data, in the form outlined above, should be required as part of Stage 3 Meaningful Use. Consistent with the position of others involved in this work, we recommend that reported quality measures should be stratified by sexual orientation and by gender identity, and there should be demonstrated reduction in disparities based on sexual orientation and gender identity for at least one of the quality measures.⁷ As the Department, the Institute of Medicine and many other authorities have recognized, LGBT individuals face specific, significant health challenges and suffer significant health disparities on the population level. Requiring participants in the incentive program to collect SOGI data, and to demonstrate how they use it in delivering health care and monitoring the quality

⁷ Washington, DC: Consumer Partnership For eHealth, *Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan*, August 2013, available at <http://www.nationalpartnership.org/research-library/health-care/HIT/leveraging-meaningful-use-to.pdf>.

of the care that they deliver, is an important step in ensuring that adequate, nondiscriminatory care is provided to persons of every gender and sexuality, and to advance our knowledge about health disparities and ways to address inequities.

Respectfully submitted,

A handwritten signature in cursive script that reads "Daniel Bruner".

Daniel Bruner, JD, MPP, Senior Director of Policy

A handwritten signature in cursive script that reads "Jennafer Kwait".

Jennafer Kwait, PhD, MHS, LGBT Policy Associate

WHITMAN-WALKER HEALTH

1710 14th Street NW

Washington, DC 20009

(202) 939-7628

dbruner@whitman-walker.org

jkwait@whitman-walker.org

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