Comments on behalf of the
American Psychological Association

RE: V. Other Topics for Consideration for the 2017 Edition Certification Criteria Rulemaking

45 CFR Part 170
RIN 0991-AB92
Voluntary 2015 Edition Electronic Health Record (EHR) Certification Criteria; Interoperability Updates and Regulatory Improvements

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The American Psychological Association (APA) is pleased to have the opportunity to submit comments on whether certification should require that Electronic health records (EHRs) technology be capable of enabling a user to electronically record, change, and access data on a patient’s sexual orientation and gender identity. APA is on record as supporting this capability as a means of improving health care and reducing health disparities for these populations.\(^1\) Social and behavioral factors contribute to the onset and progression of disease. EHRs are used to record personal health information and can be used to track health outcomes and health status of LGBT individuals and evaluate health interventions. EHRs provide information that can improve the capacity of health care systems and public health providers to plan, and also aids researchers in understanding the role of the social determinants of health.

APA would also like to take this opportunity to comment on whether the proposed code sets could be used to capture this information in a structured format. In terms of the wording of the specific questions used in EHRs, we believe that the following points are important.

1) The wording of such questions must be evidence-based and result in accurate information across all populations, including all sexual orientations and gender identities, especially those who do not identify as transgender. If individuals are confused by items, any data collected will be compromised. Further, given the problems that many sexual and gender minorities have experienced with discrimination in health care settings, these items must be carefully designed.\(^2\)

   a. Significant research effort has been invested in item design and wording for measuring sexual orientation in public health surveys. Similar efforts should be made by the federal government to determine the wording of items to be included in EHRs to accurately record patient sexual orientation. The proposed SNOWMED CT® for sexual orientation contains variables (e.g. asexual) that may conflate sexual behavior (e.g. abstinence) with sexual orientation.\(^3\) The items used in federal public health surveys (for instance, NHANES, NSDUH, NSFG and others) may provide a basis for the wording of questions for EHRs.

   b. Gender identity questions should not simply mirror those questions used for sexual orientation, but be based on unique research across all populations, including those who do not identify as transgender. Work on these types of items has only begun recently.

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2 See more at, Gender-Related Measures Overview [http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/geniuss-group-overview-feb-2013/](http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/geniuss-group-overview-feb-2013/)

2) Items in EHRs should be harmonized with the sexual orientation and gender identity (SOGI) data collected in federal public health surveys. Creating databases that can be used to map EHRs’ findings to national surveillance surveys would be the most helpful for understanding health disparities and critical for effective public health surveillance. Having disparate types of items will make research increasingly difficult and interfere with the purpose of EHRs inclusion.

3) EHRs foremost are means to record patient health information. Patient privacy and security protections should be robust and reflect the enduring nature of these records that will be seen by many over the patient’s life course. Many LGBT individuals live or may eventually live in states where there are no protections with regard to employment and family law. Individuals may face significant risk of stigma and discrimination and disclosure of this type of personal information could cause adverse events for patients.

Patients need to be assured by the provider of the privacy and security of the information they provide. Thus, continued study of best practices of maintaining privacy and security of EHRs should be a priority; this is especially important when data is transmitted across multiple health systems and between clinicians and researchers. Research and development into technology (such as tagged data elements) that could improve privacy and security, as well as strong encryption and authentication features, highlighted in the President’s Council of Advisors on Science and Technology Report to the President (PCAST) (2010), remain essential and should be robustly funded. A strong legal and regulatory framework that supports privacy and security is also important.

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