California LGBT Health & Human Services Network

November 26, 2012

Peter Lee, Executive Director
Covered California
560 J Street, Suite 290
Sacramento, CA 95814

Re: Comments on Evaluation Planning

Dear Mr. Lee,

The California LGBT Health and Human Services Network, a statewide coalition of approximately 50 organizations that provide health and social services to lesbian, gay, bisexual and transgender (LGBT) Californians, is pleased to offer the following comments regarding evaluation planning for Covered California.

The evaluation plan presented at the November 14th Board meeting will determine the success and effectiveness of Covered California in achieving its mission, part of which includes promoting health equity. To do so, Covered California must identify disparities in access, utilization and quality that may affect enrollees who are members of underserved populations. Data collection, including in the evaluation process, will be a key tool to understand and address disparities in health care access and outcomes among California's diverse communities, including communities brought together by sexual orientation or gender identity.

These comments provide an explanation of the importance of data collection on health quality and equity in California, particularly for LGBT people and their families, and offers best practices for collecting accurate data from Covered California applicants regarding sexual orientation and gender identity.

Data collection is a vital component of achieving health equity

Comprehensive and accurate data collection is indispensable to efforts to achieve equity in health for all by identifying, tracking, and eventually eliminating health disparities. Data help researchers, policy makers, and public health workers understand where disparities exist, focus interventions on the populations that need them most, and tailor these interventions to the specific needs of diverse communities.

LGBT data collection by Covered California is a natural corollary to national efforts to improve data collection on sexual orientation and gender identity that are already underway. In March 2011 the Institute of Medicine issued a landmark report on LGBT health that strongly recommended the routine collection of demographic and health data on LGBT people.[1] The Affordable Care Act also prioritizes data: the law directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors she deems relevant to reducing disparities.[2]

In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[3] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys.

This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBT individuals are more likely to be uninsured and report poorer health outcomes than the general population. Sources such as the Institute of Medicine,[4] Healthy People 2020,[5] the Substance Abuse and Mental Health Services Administration,[6] and the *National Healthcare Disparities Report* from the Agency for Healthcare Research and Quality (AHRQ)[7] indicate that these disparities include a higher risk of HIV among gay and bisexual men and transgender women,[8] increased likelihood of obesity among lesbians and bisexual women,[9] a rate of suicidal ideation among transgender people that is 25 times higher than for the general population,[10] and increased rates of depression and other mental health concerns among the LGBT population as a whole.[11]

These disparities are particularly exacerbated for those living at the intersection of multiple disparity populations, such as LGBT families living in poverty, LGBT individuals of color, and LGBT people living in rural areas. Data collection is crucial to understanding and addressing intersectional health disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

Covered California should collect comprehensive demographic data

Comprehensive data collection by Covered California on demographic factors such as race, ethnicity, sex, primary language, disability status, sexual orientation, and gender identity is a natural corollary to other state and federal efforts to gather the data necessary to inform health disparity elimination efforts. Moreover, these data are critical for the effective operation of aspects of the Exchange such as outreach, marketing, and ensuring that underserved populations are proportionally represented among Exchange customers.

Demographic data are also necessary for Covered California to ensure that its own activities and those of Qualified Health Plan (QHP) issuers are in compliance with nondiscrimination laws such as the Civil Rights Act and the Americans with Disabilities Act. Section 1557 of the Affordable Care Act specifically extends the protections of these and other federal nondiscrimination laws to the Exchanges, as entities established under Title I of the act. Federal regulations further clarify that all Exchange consumers must be afforded protection from discrimination on the basis of sexual orientation and gender identity, in addition to race, sex, disability status, and other protected factors.[12]

Recommendations for collecting demographic data through the Covered California

We therefore make the following recommendations regarding data collection by Covered California:

1. Collect <u>confidential and optional</u> information on the race, ethnicity, sex, primary language, disability status, sexual orientation, and gender identity demographics of Covered California applicants.

    - For race and ethnicity data, use the standards put forth by the Institute of Medicine in its 2009 report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*.[13]

- For primary language data, use the standards put forth by the Institute of Medicine in *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*.
- For disability data, use the standards put forth by the Department of Health and Human Services in its 2011 "Implementation Guidance on Data Collection Standards for Race, Ethnicity, Primary Language, and Disability Status."[14]
- For sex data, please see "best practices" section below.
- For sexual orientation data, please see "best practices" section below.
- For gender identity data, please see "best practices" section below.

2. Include sexual orientation and gender identity demographic questions in Covered California evaluation tools to help ensure (i) that Covered California is enrolling individuals in proportion to their representation in California's population at large; (ii) that outreach, marketing, application, and enrollment policies and activities are appropriately reaching underserved populations, including the LGBT population; (iii) that Covered California and participating QHP issuers and their QHPs are in compliance with the nondiscrimination requirements of Affordable Care Act §1557 and the federal regulations referenced above; and (iv) that LGBT Covered California enrollees are able to access high-quality health care services.

3. Create and implement robust privacy protections for all demographic data collected from Covered California applicants. To the extent these data are shared with QHP issuers, Covered California must clearly require and enforce nondiscrimination by these issuers on any protected basis—which, according to federal regulations, include race, ethnicity, sex, primary language, disability status, sexual orientation, and gender identity.[15]

4. Include a prominent and clearly worded nondiscrimination policy on all Covered California application documents and data collection instruments that is inclusive of race, ethnicity, sex, primary language, disability status, sexual orientation, and gender identity. This policy should indicate to Exchange applicants that these data are confidential and voluntary and are being collected only for the purposes of improving the services Covered California provides to its customers.

5. Train Covered California staff in assisting applicants with questions and concerns regarding the collection of any demographic data. Also train data processers on working with these data, particularly data on sex and gender identity. See below for specific recommendations.

6. Require QHP issuers, to the extent possible, to collect and report race, ethnicity, sex, primary language, disability status, sexual orientation, and gender identity data and to stratify their quality and claims data by these characteristics. Ensuring that plan evaluation tools have the capacity to collect these data will be an important component of this objective.

Best practices for collecting LGBT data

Numerous models exist for collecting demographic data on sexual orientation and gender identity. <u>These concepts include the following components: relationship status, sexual orientation, sex, and gender identity.</u> Particular attention must be paid to sex and gender identity data to ensure that the data collected are useful, comprehensible, and reflective of the lived experiences of transgender Californians.

1. **Relationship status.** Research shows that family structures in America today are increasingly varied:
    - Only 25 percent of American households consist of a married man and woman and their children.[16]
    - According to 2010 Census data, California is home to over 98,000 same-sex couples.[17]
    - Over 15,600 of these couples are raising children.[18]

    In order to accurately reflect the realities of California's families, the Exchange must be able to capture information about same-sex couples and their children, among other diverse family structures. The question below is based on relationship status questions developed by the U.S. Census Bureau[19] and is reflective of the diversity of relationships legally recognized by California, which include same- and different-sex domestic partnerships and marriages. As a corollary to LGBT inclusion in the relationship status question, the Covered California application, as well as other data collection instruments, should consistently use "Parent 1" and "Parent 2" instead of "Mother" and "Father."

    What is your relationship status?
    - *Single*
    - *Married to an opposite-sex spouse*
    - *Married to a same-sex spouse*
    - *In an opposite-sex domestic partnership or civil union*
    - *In a same-sex domestic partnership or civil union*
    - *Divorced*
    - *Widowed*

2. **Sexual Orientation.** In order to better understand the significant health disparities associated with minority sexual orientation, Covered California should collect optional data on the sexual orientation of applicants. The question below is based on research by the Williams Institute, a national sexual orientation and gender identity law and policy think tank at the UCLA School of Law.[20] It is currently being used on numerous state and local surveys[21] and in administrative data collection efforts by federally supported health programs. It is also the basis for current efforts by the National Center for Health Statistics to develop a sexual orientation question for federally supported health surveys.[22] This question, similar to questions asking about race or ethnicity, should be accompanied by appropriate training for the staff involved in collecting and processing these data to ensure that responses are accurately collected, recorded, and interpreted.

    Do you consider yourself to be:
    - *Straight or heterosexual*
    - *Gay or lesbian*
    - *Bisexual*
    - *Something else (write in)*

3. **Sex.** As mentioned above, the data collected on this application are important tools for ensuring that the Exchanges and QHP issuers fully comply with the nondiscrimination requirements of federal regulations and ACA §1557. Section 1557 includes protections on the basis of sex, which the Office for Civil Rights at the Department of Health and Human Services has indicated

includes gender identity.[23] Therefore, the application should reflect the health insurance needs and experiences of the transgender population.

In order to do so, the question regarding sex should specify *sex assigned at birth*, which is the sex listed on the original birth certificate. The responses to this question are the traditional concepts of sex as male or female, meaning that the question will be comprehensible to non-transgender people and that the long-term usefulness of existing sex data will not be compromised. The responses to this question are read in combination with the responses to the question on gender identity described below in order to provide accurate information on both the transgender and non-transgender population.

4. **Gender identity.** The Institute of Medicine reports that transgender people, particularly transgender people of color, are more likely than the general population to be uninsured and face significant health and health care access disparities.[24] These disparities include higher rates of conditions such as HIV/AIDS, substance use, and mental health concerns such as depression, anxiety, and suicide, as well as obstructed access to urgent and routine medical care. In fact, the 2011 *National Healthcare Disparities Report* identifies transgender individuals as the most vulnerable segment of the LGBT population.

   A lack of health insurance coverage is a major driver of health and health care access disparities among the transgender population. According to the AHRQ report, which cites data from a national study of more than 6,400 transgender individuals, more than 30 percent of transgender people of color lack health insurance coverage, and approximately half of transgender respondents had to postpone medically necessary care for financial reasons.[25] Further, transgender people are significantly more likely than the general population to live in poverty,[26] meaning that a substantial proportion of the transgender population will be eligible for subsidies through Covered California. In order to identify and connect these individuals with appropriate coverage, and to stratify quality data connecting with transgender enrollees, Covered California should collect data on gender identity in addition to data on sex.

   Like race, ethnicity, and sexual orientation, this question should be optional. Because the Affordable Care Act prohibits rating on the basis of sex, including gender identity, and health status, including a transgender medical history, this question is purely for demographic purposes. The question described below is based on questions already in use on some state and local health surveys[27] and federally supported health programs.[28] This question should also be accompanied by appropriate training for the staff involved in collecting and processing these data to ensure that responses are accurately collected, recorded, and interpreted. Information on correctly using the gender identity question can be found in the 2012 "Guidance for HIV Surveillance Programs: Working with Transgender-Specific Data" developed by the Centers for Disease Control and Prevention.[29]

   What is your current gender identity? Gender identity is an individual's internal understanding of one's own gender.

   - *Male*
   - *Female*
   - *Transgender, female to male*
   - *Transgender, male to female*

Conclusion

A comprehensive range of demographic data on the protected classes of race, ethnicity, sex, primary language, disability status, sexual orientation and gender identity is a necessary and vital component of successful health reform efforts in California. The California LGBT Health & Human Services Network strongly encourages development of a comprehensive data collection strategy and coordinated approach to ensure Covered California has the capacity to collect, protect, and use these data to help eliminate health disparities and achieve health equity for all.

Sincerely,

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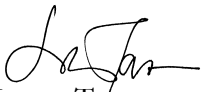

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Notes

[1] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx
[2] Affordable Care Act §4302

[3] Department of Health and Human Services. 2011. "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations." Available from http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209

[4] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.

[5] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[6] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBT Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBT-Populations/SMA12-4684

[7] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[8] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health" (citing: Centers for Disease Control and Prevention. 2010. "HIV and AIDS among gay and bisexual men." Available from http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-MSM-FINAL508COMP.pdf)

[9] *Id.* (citing: Struble CB, Lindley LL, Montgomery K, et al. Overweight and obesity in lesbian and bisexual college women. J Am College Health. 2010;59(1):51-6).

[10] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[11] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health" (citing: Hughes TL. Chapter 9: Alcohol use and alcohol-related problems among lesbians and gay men. *Ann Rev of Nurs Res* 2005;23:283-325; Lee GL, Griffin GK, Melvin CL. Tobacco use among sexual minorities in the USA: 1987 to May 2007: A systematic review. *Tob Control* 2009;18:275-82; Lyons T, Chandra G, Goldstein J. Stimulant use and HIV risk behavior: The influence of peer support. *AIDS Ed and Prev* 2006;18(5):461-73; Mansergh G, Colfax GN, Marks G, et al. The circuit party men's health survey: Findings and implications for gay and bisexual men. *Am J Public Health*. 2001;91(6):953-8; Xavier J, Honnold J, Bradford J. The health, health-related needs, and lifecourse experiences of transgender Virginians. Virginia HIV Community Planning Committee and Virginia Department of Health. Richmond, VA: Virginia Department of Health; 2007. Available from http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORTVol1.pdf)

[12] 45 C.F.R. §155.120(c)(2)

[13] Institute of Medicine. 2009. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Available from www.iom.edu/Reports/2009/RaceEthnicityData.aspx

[14] Department of Health and Human Services. 2011. "Implementation Guidance on Data Collection Standards for Race, Ethnicity, Primary Language, and Disability Status." Available from http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.shtml

[15] 45 C.F.R. §156.200(e)

[16] Talaris Institute. 2010. "Parenting in a Changing World." Available from http://www.talaris.org/our-research/parenting-in-a-changing-world/

[17] The Williams Institute. 2011. "California Census Snapshot: 2010." Available from http://williamsinstitute.law.ucla.edu/wp-content/uploads/Census2010Snapshot_California_v2.pdf

[18] Ibid.

[19] U.S. Census Bureau and the Williams Institute. 2010. "LGBT Fact Sheet." Available from http://2010.census.gov/partners/pdf/factSheet_General_LGBT.pdf. *See also* Theresa J. DeMaio and Nancy Bates. 2012. "New Relationship and Marital Status Questions: A Reflection of Changes to the Social and Legal Recognition of Same-Sex Couples." Center for Survey Measurement, Research and Methodology Directorate Research Report Series (Survey Methodology #2012-02). U.S. Census Bureau. Available from http://www.census.gov/srd/papers/pdf/rsm2012-02.pdf

[20] Sexual Minority Assessment Research Team. The Williams Institute. 2009. "Best Practices for Asking Questions about Sexual Orientation on Surveys." Available from http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf

[21] *See e.g.* California Health Interview Survey. 2011. "CHIS 2009 Adult Questionnaire Version 3.4." Available from http://www.chis.ucla.edu/pdf/CHIS2009adultquestionnaire.pdf; New Mexico Department of Health. 2010. "New Mexico's Progress in Collecting Lesbian, Gay, Bisexual, and Transgender Health Data and its Implications for Addressing Health Disparities." Available from http://nmhealth.org/erd/healthdata/pdf/2010_LGBT_Report.pdf

[22] Department of Health and Human Services. 2011. "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations." Available from http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209

[23] Letter from Leon Rodriguez to Maya Rupert. 2012. Available from http://www.scribd.com/doc/102491874/HHS-Response-1557-7-12-12

[24] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

[25] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[26] Grant, JM, Mottet LA, Tanis J, et al. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Available from http://www.thetaskforce.org/reports_and_research/ntds

[27] *See e.g.* Landers, S. and P. Gilsanz. 2009. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Persons in Massachusetts. A survey of health issues comparing LGBT persons with their heterosexual and non-transgender counterparts*. Massachusetts Department of Public Health. Available from http://www.mass.gov/Eeohhs2/docs/dph/commissioner/lgbt_health_report.pdf

[28] *See e.g.* Health Resources and Services Administration. 2012. "Annual Ryan White HIV/AIDS Program Services Report (RSR) Instruction Manual." Available from http://hab.hrsa.gov/manageyourgrant/files/hab2011rsrinstrmanual.pdf; Substance Abuse and Mental Health Services Administration. 2012. Government Performance and Results Act (GPRA) "Client Outcome Measures for Discretionary Programs Question-By-Question Instruction Guide." Available from https://www.samhsa-gpra.samhsa.gov/CSAT/view/docs/SAIS_GPRA_Services_Tool_QxQ_final.pdf.

[29] Centers for Disease Control and Prevention. 2012. "Guidance for HIV Surveillance Programs: Working with Transgender-Specific Data."