COVERED CALIFORNIA: Stakeholder Questions
CalHEERS Requirements

COVERED CALIFORNIA welcomes your comments on the CalHEERS requirements that will be used to develop the system. Please use the table below to provide your input. Please submit your comments to the Exchange at info@hbex.ca.gov by close of business Friday, November 30, 2012. The principles and options are laid out in a Board options paper available on the Exchange website. Please use the table below to provide your input. Please submit your comments to the Exchange at info@hbex.ca.gov by close of business Friday, November 30, 2012.

Name	Organization	Email	Phone
Kate Burch, Network Coordinator	**California LGBT Health & Human Services Network**	**kburch@health-access.org**	**916-497-0923 x200**

The California LGBT Health and Human Services Network is a statewide coalition of approximately 50 organizations that provide health and social services to lesbian, gay, bisexual and transgender (LGBT) Californians. We are pleased to offer the following comments regarding CalHEERS requirements to help ensure that Covered California has the capacity to collect accurate data about LGBT individuals and families.

Comprehensive and accurate data collection is an essential piece of achieving health equity, enabling the identification, tracking, and eventual elimination of health disparities. 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. The Affordable Care Act directs the U.S. Secretary of Health and Human Services to collect data on health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors she deems relevant to reducing disparities.[1] The Institute of Medicine issued a report in March 2011 recommending the routine collection of health and demographic data on LGBT people.[2] In June 2011, Secretary Sebelius committed the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys in the new LGBT Data Progression Plan.[3]

We strongly encourage Covered California to build in the capacity to collect data about sexual orientation and gender identity, as well as the ability to accurately recognize the myriad types of families that exist in California.

[1] Affordable Care Act §4302
[2] 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
[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

Requirement Number	Comment
BR8	"Family" should be expansive enough to include married couples, domestic partners, and children who are the legally the child of one or both people in the marriage/partnership.
BR23	"Family" should be expansive enough to include married couples, domestic partners, and children who are the legally the child of one or both people in the marriage/partnership.
BR37	Optional demographic data should include the following. See **Best Practices for Collecting LGBT Data** at the end of this document for more explanation of these items. Sex Assigned at Birth: sex listed on the original birth certificate Gender Identity: 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 • Other Sexual Orientation: Do you consider yourself to be • Straight or heterosexual • Gay or lesbian • Bisexual • Something else (write in) Relationship Status: 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
BR56	CalHEERS should have functionality calculate household size and income for both California programs and federal considerations.

Requirement Number	Comment
BR69	CalHEERS should have functionality calculate household size and income for both California programs and federal considerations.
BR74	CalHEERS should have functionality calculate household size and income for both California programs and federal considerations.
BR76	Eligibility qualifying events should include changes divorce or dissolution of domestic partnership that might result in an individual losing coverage through their spouse/partner's employer or family insurance plan.
BR83	Change in household should include entering into or dissolution of a domestic partnership.
BR97	Given the large number of insurance plans that have specific exclusions for transition-related care, CalHEERS should include transition-related care as one of the benefit gaps it tracks and highlights.
BR101	Most doctors are untrained or undertrained in the health care needs of lesbian, gay, bisexual, and transgender individuals.[4] This makes it difficult for LGBT individuals to find providers who are able to meet their health care needs. In the Provider Directory, CalHEERS should indicate providers who have received training on LGBT health needs.
BR102	Given the large number of insurance plans that have specific exclusions for transition-related care, CalHEERS should provide information about transition-related care for each plan a user selects for comparison.
BR267	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR287	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR292	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR294	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR295	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.

[4] Obedin-Maliver, J. et al. *Lesbian, Gay, Bisexual, and Transgender–Related Content in Undergraduate Medical Education*. Journal of American Medical Association, Sept. 2011;306(9):971-977. Available online at http://jama.jamanetwork.com/article.aspx?articleid=1104294.

Requirement Number	Comment
BR296	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR301	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
BR338	Demographics should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
SR19	Optional demographic data should include the following. See **Best Practices for Collecting LGBT Data** at the end of this document for more explanation of these items. Sex Assigned at Birth: sex listed on the original birth certificate Gender Identity: 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 • Other Sexual Orientation: Do you consider yourself to be • Straight or heterosexual • Gay or lesbian • Bisexual • Something else (write in) Relationship Status: 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

Requirement Number	Comment
SR98	Given the large number of insurance plans that have specific exclusions for transition-related care, CalHEERS should provide information about transition-related care for each plan a consumer selects for comparison.
SR136	CalHEERS should include entering into or dissolution of domestic partnership as an option for change in family status. Employees should also be able to update their account with a change in gender identity.
SR236	Reports on demographic data should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
SR255	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
SR265	Reports should include relationship status, sex assigned at birth, gender identity, and sexual orientation.
TR103.2.2	When receiving information from the AIM system, the "gender" information marker should be correlated with "sex assigned at birth" in the CalHEERS system.

Best Practices for Collecting LGBT Data

Numerous models exist for collecting demographic data on sexual orientation and gender identity. These concepts include the following components: relationship status, sexual orientation, sex, and gender identity. 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.[5]
    - According to 2010 Census data, California is home to over 98,000 same-sex couples.[6]
    - Over 15,600 of these couples are raising children.[7]

[5] Talaris Institute. 2010. "Parenting in a Changing World." Available from http://www.talaris.org/our-research/parenting-in-a-changing-world/
[6] The Williams Institute. 2011. "California Census Snapshot: 2010." Available from http://williamsinstitute.law.ucla.edu/wp-content/uploads/Census2010Snapshot_California_v2.pdf
[7] Ibid.

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[8] 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.[9] It is currently being used on numerous state and local surveys[10] 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.[11] This question, similar to questions asking about race or ethnicity,

[8] 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

[9] 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

[10] *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

[11] 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

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.[12] 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.[13] 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.

[12] Letter from Leon Rodriguez to Maya Rupert. 2012. Available from http://www.scribd.com/doc/102491874/HHS-Response-1557-7-12-12
[13] 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

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.[14] Further, transgender people are significantly more likely than the general population to live in poverty,[15] 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[16] and federally supported health programs.[17] 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.[18]

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*

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[14] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf
[15] 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
[16] *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
[17] *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.
[18] Centers for Disease Control and Prevention. 2012. "Guidance for HIV Surveillance Programs: Working with Transgender-Specific Data."