

Counting Trans* Patients

A Community Health Center Case Study

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Abstract With the Affordable Care Act revolutionizing the US health care system, the importance of collecting clinical, demographic, operational, and utilization data has exponentially increased for community health centers (CHC). Data collection of gender and gender identity presents a unique set of challenges for medical settings. One central challenge is the conflict between, on one hand, the need to know and use patients' preferred names, gender identities, and pronouns to establish trust and safety and, on the other hand, institutional requirements to know and use patients' legal names and gender markers with insurance companies and pharmacies. This essay examines how a community-based LGBTQ community health center, Lyon-Martin Health Services, collects and reports data about gender identity and how this process has changed over time. Lyon-Martin strongly supports the use of the two-step gender data collection method, which allows clinicians to have necessary information related to patients' anatomy-based health care while simultaneously honoring and respecting patients' gender identity and preferred pronouns. Collecting precise information about patient sex and gender is vital to providing not only respectful care but also medically appropriate care. The ability to quantify and justify the services provided by CHCs is a key part of keeping clinics open and thriving, from securing grant support to implementing internal quality improvement efforts to provide the best care for trans* patients. The shift toward electronic medical records and electronic practice management systems is also highlighted, including billing and clinical practice challenges due to narrowed gender options written into practice-management and billing software.

Keywords trans* health care, health technology, community health center, trans* data collection

With the Affordable Care Act revolutionizing the US health care system, the importance of collecting clinical, demographic, operational, and utilization data has exponentially increased for community health centers. Being able to quantify what we, as a community health center, do and whom we serve is expected, if not required, for governmental reporting, private funders, and quality improvement efforts. This type of data collection generally includes basic demographic information like gender, sexual orientation, race/ethnicity, and income. For clinics and hospitals, this information may also inform the type of health care received. Data collection of gender and gender identity presents a

unique set of challenges for medical settings for a variety of reasons. One central challenge is the conflict between, on one hand, the need to know and use patients' preferred names, gender identities, and pronouns to establish trust and safety and, on the other hand, institutional requirements to know and use patients' legal names and gender markers with insurance companies and pharmacies. These challenges persist and perhaps even increase with the proliferation of electronic medical records and electronic health systems.

Gender Identity: One- versus Two-Step Method

The World Professional Association for Transgender Health (WPATH) Electronic Medical Record (EMR) working group recommends the two-step method of gender collection adopted by the US Centers for Disease Control and Prevention in 2011 (Deutsch et al. 2013). The two-step, or two-question, method involves asking on demographic forms about current gender identify *first*, then about previous gender (and/or sex) assignment, to honor the importance of current identity over past assignment.

This method of assessing gender in the social and medical sciences is considered more robust than a single-gender question (Tate, Ledbetter, and Youssef 2013). The authors recommend first asking "What is your current gender identity?" followed by "What gender were you assigned at birth?" This is opposed to a single-question assessment—for example, "What is your gender?" Charlotte Chuck Tate, Jay N. Ledbetter, and Cris P. Youssef argue that the two-step method allows for greater identification of transgender subjects (almost three times as many as the single-step question), less missing data, higher response rate (there was seven times more missing data in the one-step method than the two-step one), and specific identification of cisgender subjects,¹ a data point that is impossible to extract without the two-step method. While previous studies of transgender health have reported using the two-step method (Deogracias et al. 2007; Melendez et al. 2006), it is not commonly found in other large-scale data collection efforts.

This essay examines how a community-based LGBTQ community health center, Lyon-Martin Health Services, collects and reports data about gender identity and how this process has changed over time. First we present a brief review of Lyon-Martin's history, current services, and patient demographics followed by a short examination of how gender-identity data collection has changed over time. Then we highlight specific gender-identity data collection and reporting challenges. Finally, we explore future directions and challenges based on the implementation of electronic medical records and other automated health systems.

Lyon-Martin Health Services

Lyon-Martin Health Services (LMHS) is a nonprofit community health center founded in 1979 by a group of medical providers and health activists.² Today, as a federally qualified health center,³ Lyon-Martin offers an integrated model of primary care and behavioral health to patients who identify as women and/or transgender, regardless of ability to pay. LMHS currently has twenty-five full- and part-time staff members and serves approximately two thousand patients a year. It serves a highly diverse patient population, including 32 percent trans*,⁴ 49 percent LGBQ (lesbian, gay, bisexual, and queer), 43 percent people of color, and approximately 80 percent patients below the federal poverty line. LMHS is also well-known for its transgender health education program, Project HEALTH, a joint program with the Transgender Law Center that aims to expand health care access for trans* patients.⁵

LMHS Gender Data Collection Changes over Time

As mentioned above, Lyon-Martin's origin was as a service for cisgender lesbian women. However, its mission statement and patient population have shifted over time. Figure 1 reflects the total number of patients from data available from 2003 to 2013.

These data from the California Office of Statewide Health Planning and Development (OSHPD) also include gender categories, although there are only two genders available in these reports. The figure reflects an increasing number of LMHS patients who are categorized as male. These reports are an example of the potential inaccuracies in gender data collection. Not only are there only two genders available in the report; it is impossible to know, based on these reports, if these numbers reflect patients' sex assigned at birth or patients' gender identity. For example, the increase in male patients could reflect an increase in FTM or trans male patients if these reports reflect current gender identity. Alternatively, if these reports reflect sex assigned at birth, the increase in male patients reflects the increasing number of trans women in the patient population.

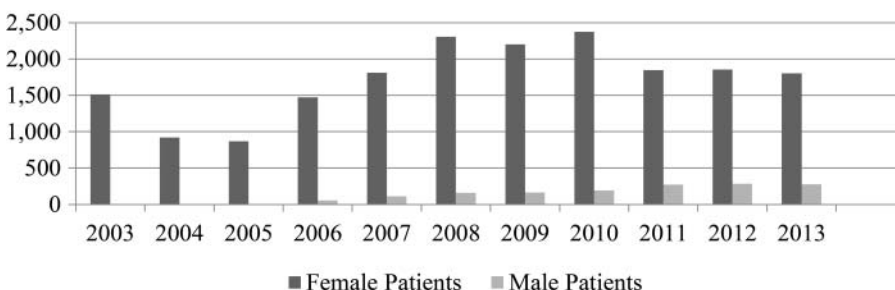


Figure 1. LMHS patient population by gender, 2003–2013

Our past patient demographic forms reflect a shift in gender data collection as well. Based on a review of past forms, table 1 shows changes in our assessments of gender, sex assigned at birth, sexual orientation, and pronoun preference in the last fifteen years. These are based on charts from trans* patients who have had LMHS as their primary-care home for five or more years. Forms used before 1999 were not available.

Additional gender categories (such as genderqueer) were added over time based on patients' response to the open-ended "Other" option. Patients are also increasingly reporting "my name" as a preferred pronoun, though this has not yet been formalized into our data collection forms. Our most recent revision includes the addition of a third gender assessment: "For billing purposes if you have insurance, what gender do they have on record for you?" This allows us to bill insurances without rejection, since every piece of demographic information entered for a patient must match what the insurance company has on file before a bill can be processed and paid.

Current LMHS Gender and Sexual Orientation Data Collection Procedures

Lyon-Martin collects patient gender identity and sexual orientation data at various stages of the clinical encounter. New patients or patients reestablishing care after more than three years are asked to complete a patient intake demographic form that asks about gender identity, sex assigned at birth, insurance gender marker, sexual orientation, and pronoun preferences, all as separate questions. These forms are available in English and Spanish (see fig. 2).

Additionally, patients complete update forms (given at an annual exam or more often if the patient notes a change in contact information), where we ask questions related to gender identity (see fig. 3).

Lyon-Martin strongly supports the use of the two-step gender data collection method. This method allows clinicians to have necessary information related to patients' anatomy-based health care while simultaneously honoring and respecting patients' gender identity and preferred pronouns. Additionally, this method also allows for more complete data collection information from a quality-management and data-reporting perspective. For example, in an analysis of patients seen from May to November 2013, if we asked only about gender identity, 30 percent of our patients would be counted as trans*. Compare this to the two-step method, where, instead, 32 percent of our patients are counted as trans*. It is also important to note that these two figures reflect a collapse of noncisgender gender identities (such as transgender, genderqueer, or nonbinary) under one trans* umbrella term. In addition, the two-step method also makes another option available to our patients: that one can be trans* without

Table 1. Changes in LMHS data collection forms (1999–2013)

<i>Year</i>	<i>Form Type</i>	<i>Gender Identity Assessed (Yes/No)</i>	<i>Gender Identity Answer Options</i>	<i>SAAB^a Assessed (Yes/No)</i>
1999–2001	Health history	No (see sexual orientation)	N/A	No
2002	Patient registration	Yes (“Gender”)	Female Transgender (M-F/F-M) Other _____	No
2005	Grant data form	No	N/A	No
2006 ^b	Patient demographic	Yes (“What is your gender?” [mark one])	Female Male Transgender/ transsexual MtF Transgender/ transsexual FtM Other _____ Decline	Yes (“What is your sex?” [mark one])
2010	Patient intake	Yes	Female Male Decline	Yes
2012–now	Patient intake	Yes	Female Male Transgender MtF Transgender FtM GenderQueer Other _____ Decline	Yes

^aSAAB = sex assigned at birth.

^b2006 is the first record of the two-step gender assessment’s use at LMHS.

^c2006 is the first year intersex appears as an option for SAAB.

necessarily having a trans identity (e.g., marking male for sex and female for gender). For example, a trans woman can choose female as her gender versus transgender or MTF on an intake form while still indicating that she was assigned male at birth. This flags the staff to give this patient trans*-specific health care while respecting her preferred gender identity. While this possibility has not been

<i>SAAB Answer Options</i>	<i>Sexual Orientation Assessed (Yes/No)</i>	<i>Sexual Orientation Answer Options</i>	<i>Pronoun Assessed (Yes/No)</i>	<i>Pronoun Answer Options</i>
N/A	Yes (“How do you identify yourself, sexually?”)	Lesbian Bisexual Heterosexual Transgender Celibate	No	N/A
N/A	No	N/A	No	N/A
N/A	Yes (open-ended with “sexual orientation” as prompt)	Some patients wrote in transgender as sexual orientation	No	N/A
Female Male Intersex ^c Other _____ Decline	Yes (Decline option introduced)	Lesbian Gay Bisexual Heterosexual/straight Queer Celibate Other _____ Decline	Yes	She/Her He/Him Sie/Zie/Hir Other _____
Male Female Intersex Other _____ Decline	Yes	Lesbian Queer Bisexual Gay Celibate Heterosexual	Yes	She/Her He/Him Zee/Hir
Male Female Intersex Other _____ Decline	Yes	Lesbian Gay Queer Bisexual Heterosexual Celibate Other _____ Decline	Yes	She/Her He/His They/Them/Their Ze/Hir Other _____

noted in other literature on the two-step method, we believe that it allows patients to most clearly express their preferred gender identity.

LMHS Gender Data Collection Challenges

Even the more accurate two-step method of gender data collection brings challenges when collapsing gender categories for internal quality control analysis as well as when reporting to outside entities, such as funding agencies, foundations,

and health departments. For example, genderqueer patients or those who utilize the self-defined “other” category are routinely combined with both trans men and trans women in data analysis under one trans* umbrella for reporting purposes. Additionally, outside entities often want or need sex data in order to match our records to other databases. We know internally that sex data do not translate

Lyon-Martin Health Services
Patient Demographic Information

Date: _____ LMHS Chart #: _____

Preferred Name: _____ Legal Name: _____

Home Address (including city, state, and zip): _____

Mailing Address (including city, state, and zip): _____

Date of Birth: _____ SSN: _____-_____-_____

Phone Number: _____ Email Address: _____

Can we leave you a confidential message at this phone number? Yes No

If you don't have contact information, what other social service agencies do you frequent?

What type of insurance(s)/coverage(s) do you have? *We treat everyone regardless of ability to pay.*

None CDP San Francisco Health Plan Medicare
 Healthy SF Family Pact Medi-Cal Other: _____

For billing purposes, if you have insurance, what gender do they have on record for you? Female Male

If you have been seen at San Francisco General Hospital, what is your medical record number? _____

My head of household is: _____, & additional # members: _____. My household's annual income is: _____
Due to Federal Regulations, we must ask all patients their household size and income, regardless of health insurance status. Household members include those persons living in the same home who are related by birth, marriage, registered domestic partnership, or adoption. If you are interested in applying for our Sliding Scale Program, please request an application from the Front Desk as providing this information here does not constitute an application.

My gender identity is: <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Trans (MTF) <input type="checkbox"/> Trans (FTM) <input type="checkbox"/> Genderqueer <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My sex assigned at birth is: <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Intersex <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My marital status is: <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Registered Domestic Partner <input type="checkbox"/> Widowed <input type="checkbox"/> Unmarried Partner <input type="checkbox"/> Legally Separated <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline
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My sexual orientation is: <input type="checkbox"/> Lesbian <input type="checkbox"/> Gay <input type="checkbox"/> Queer <input type="checkbox"/> Bisexual	<input type="checkbox"/> Heterosexual <input type="checkbox"/> Celibate <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My pronoun preference is: <input type="checkbox"/> She/her <input type="checkbox"/> He/his <input type="checkbox"/> They/Them/Their <input type="checkbox"/> Zie/Hir <input type="checkbox"/> Other: _____
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I live (please check all that apply):
 In a house or apartment or SRO or hotel
 In a shelter
 In a transitional or treatment program
 In an RV or vehicle
 My situation is temporary and/or unstable
 On the street

I am a veteran: Yes No
I am a seasonal agricultural worker: Yes No

Emergency Contact: _____
Relationship: _____
Phone Number: _____

I am Hispanic/Latin@: Yes No
My race is:
 Native American and/or Alaskan Native
 Asian
 Hispanic or Latin@
 Other Pacific Islander
 Black/African American
 More than one race
 Caucasian or White
 Other: _____
 Native Hawaiian
 Decline

My preferred language is:
 English
 Spanish
 Other: _____
 Decline

For Office Use Only
 Entered into EPM by: _____ on: _____

Figure 2. Lyon-Martin Health Services demographic forms (as of August 2014)

automatically to our patients' current gender identities or pronoun preferences, but other agencies with less transgender cultural competency may not consider or understand this. Thus we ran into a customer service debacle earlier this year when patient data, including sex but not gender, provided for a utilization analysis was then used to infer pronoun preferences for a mailed patient satisfaction survey. Since we had such robust data from the two-step method and collecting pronoun preferences, we were able to quickly identify which patients had been misgendered and place outreach calls. Nonetheless, it was a poignant reminder of how challenging collecting patient-centered gender data can be when one has to translate them for outside entities that do not have the same diverse understanding of gender.

While it is known that binary gender options (male/female) offered by entities such as insurance companies or government agencies directly conflict with the wideness of the gender spectrum, we find that this is also true for other agencies tracking LMHS patients or patient outcomes. Required reporting for grant-giving foundation and health department data rarely accommodates patient gender information beyond the binary gender options. This sometimes means that nonbinary (genderqueer, identifying by name only) patients either get left out of data collection completely or are misgendered in the data reporting process by reversion to their sex assigned at birth for data purposes, especially if they are a part of specific reporting populations such as homeless patients or

Lyon-Martin Health Services Patient Demographic Update						LMHS Chart #: _____
Date: _____		Preferred Name: _____		Legal Name: _____		
Address (including city, state, and zip): _____						
Phone Number: _____			Email Address: _____			
Can we leave you a confidential message at this phone number? Yes No						
If you don't have contact information, what other social service agencies do you frequent?						
What type of insurance(s)/coverage(s) do you have? <i>We treat everyone regardless of ability to pay.</i>						
<input type="checkbox"/> None	<input type="checkbox"/> CDP	<input type="checkbox"/> San Francisco Health Plan	<input type="checkbox"/> Medicare			
<input type="checkbox"/> Healthy SF	<input type="checkbox"/> Family Pact	<input type="checkbox"/> Medi-Cal	<input type="checkbox"/> Other: _____			
For billing purposes, if you have insurance, what gender do they have on record for you? <input type="checkbox"/> Female <input type="checkbox"/> Male						
My head of household is: _____, & additional # members: _____. My household's annual income is: _____						
<small>Due to Federal Regulations, we must ask all patients their household size and income, regardless of health insurance status. Household members include those persons living in the same home who are related by birth, marriage, registered domestic partnership, or adoption. If you are interested in applying for our Sliding Scale Program, please request an application from the Front Desk as providing this information here does not constitute an application.</small>						
My gender identity is:	<input type="checkbox"/> Trans (MTF)	My pronoun preference is:	<input type="checkbox"/> They/Them/Their	My sexual orientation is:	<input type="checkbox"/> Bisexual	
<input type="checkbox"/> Female	<input type="checkbox"/> Trans (FTM)	<input type="checkbox"/> She/her	<input type="checkbox"/> Zie/Hir	<input type="checkbox"/> Lesbian	<input type="checkbox"/> Heterosexual	
<input type="checkbox"/> Male	<input type="checkbox"/> Genderqueer	<input type="checkbox"/> He/his	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Gay	<input type="checkbox"/> Celibate	
	<input type="checkbox"/> Other: _____			<input type="checkbox"/> Queer	<input type="checkbox"/> Other: _____	
	<input type="checkbox"/> Decline			<input type="checkbox"/> Decline		
I live (please check all that apply):						
<input type="checkbox"/> In a house or apartment or SRO or hotel	<input type="checkbox"/> On the street	<input type="checkbox"/> In a transitional or treatment program				
<input type="checkbox"/> In an RV or vehicle	<input type="checkbox"/> In a shelter	<input type="checkbox"/> My situation is temporary and/or unstable				
For Office Use Only: Entered into EPM by: _____ on: _____						

Figure 3. Lyon-Martin Health Services demographic update form (as of July 2014)

HIV-positive patients. Additionally, patients who may not choose to identify as trans* on their intake forms, such as the example in the previous section, still need to be counted as transgender for specific grant programs to provide an accurate reflection of the amount of transgender health care we provide.

LMHS Electronic Practice Management and Electronic Health Records Challenges

As implementation of electronic medical records and other automated health systems increases, we anticipate continued challenges for accurate collection of gender data for patient populations like those at Lyon-Martin and, indeed, all health organizations. The challenge we faced in 2013 with misgendering of patients during a utilization analysis with an outside agency is one example of the ways in which automated health systems like those in electronic practice management (EPM), electronic medical records (EMR), or electronic health records (EHR) may not be sophisticated enough to deal with more than two genders (male and female). We have worked closely with the software designers during our ongoing EHR implementation process to make the systems as flexible as possible for patient demographic data collection. However, the software has its own limitations and thus we continue to adapt by making clinic-level procedural changes or work-arounds in order to ensure that health center staff identify our patients by their current preferred name and pronoun. Many EHRs also automate functions based on patient gender, such as which anatomical systems providers should review with patients. For example, a patient with gender marked female would have a provider prompt to review for pap smears and breast exams, while a male patient would be prompted for prostate screenings. Discrepancies between a patient's preferred gender identity and anatomical medical needs created by automated health systems provide a significant barrier to trans* patients' ability to receive safe, competent medical care.

M. B. Deutsch and colleagues (2013), from the World Professional Association for Transgender Health EMR working group, provide specific recommendations for EMR and transgender patients, including utilization of optional data collection fields within the software as well as means for tracking patients' gender-related medical treatments and current anatomy. LMHS has utilized these optional data fields within our current EPM software; we chose to add sex assigned at birth, patient preferred name, preferred pronoun, and sexual orientation. However, only four optional fields could be added for the entire patient record, limiting our ability to collect more detailed information on other demographics beyond what is built into the existing program. The main challenge is incongruence between preferred gender and the gender reflected on patients' insurance cards. From April 2013 to February 2014, our schedule pulled from the preferred name, but this resulted in billing staff having to change individual

patient gender for each bill. This system was not sustainable with our patient load and resulted in increased billing errors and automatically denied claims based on “incorrect” patient information. Currently, the system pulls a patient’s legal name for all billing documents in order to interface properly with outside systems such as pharmacies or outside labs. This issue also resulted in the most recent edits to our demographic form to assess insurance-identified gender. The preferred-name field is used for appointment interfacing such as searching for a patient within EPM or appointment reminder calls.

Future Directions and Challenges

We agree with Deutsch and colleagues’ recommendations and hope that providing information about the challenges we have faced will help other clinics and hospitals move forward with respectful, accurate gender and sex data collection. Collecting precise information about patient sex and gender is vital to providing not only respectful care but also medically appropriate care. The sweeping changes in health care as a result of the Affordable Care Act have already started to impact transgender individuals, especially those who were previously unable to access health care. However, this change also comes with the challenges highlighted in this essay, including clashes between legal gender, preferred gender, and insurance companies and the necessity for individual providers to work around the binary-focused private or public insurance systems (Murtha 2014). Our ability to quantify and justify the services we provide and the individuals we serve is a key part of keeping our clinic open and thriving, from securing grant support to implementing internal quality improvement efforts to provide the best care for our patients. The Affordable Care Act’s expanded insurance coverage for trans* patients also means that the two-step method may need to evolve into three or more steps in the health care setting, as our most recent demographic form revisions indicate. All the pieces of demographic data for a patient must match across systems for the insurance billing process to work smoothly or even to work at all. For us, that means that we lost the most accurate patient data because of EPM limitations in number of optional fields; sex assigned at birth was replaced with sex assigned to insurance so that billing requests would move forward. This loss of accuracy is small but significant and will become increasingly so as more and more trans* individuals interact with the health care system under the Affordable Care Act.

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Notes

1. The website for Basic Rights Oregon, an LGBT rights organization, defines cisgender (or cissexual) as a term that describes “people who, for the most part, identify as the gender they were assigned at birth” (Basic Rights Oregon 2011).
2. For a full history of Lyon-Martin, see Lyon-Martin Health Services 2014.
3. Federally Qualified Health Centers (FQHCs) must serve an underserved area or population, offer a sliding fee scale, provide comprehensive services, have an ongoing quality assurance program, and have a governing board of directors (see HRSA 2014).
4. The use of the term *trans** reflects an adaptation of web-based language taken up by the trans* community. The * (asterisk) is used as a wildcard in web searches by acting as a placeholder or a fill-in-the-blank symbol. This symbol or representation has been applied to gender identification to expand and include “folks who identify as transgender and transsexual (the terms usually understood as included when the prefix trans is used on its own) as well as other identities where a person does not identify with the gender they were assigned at birth” (Jones 2013).
5. For more information about Project HEALTH, see Project HEALTH 2014.

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