

Building Quality Improvements to Advance Health Care Equality: New Demographic and Evaluative Measures for Sex, Gender Identity, and Sexual Orientation

Overview

Disparities in receiving equitable access to health care and quality of healthcare received is an ongoing issue for patients who identify as LGBTQI (Lesbian, Gay, Bisexual, Transgender, Queer, Intersexual)¹. Many Press Ganey clients are already working diligently to improve access, safety, and quality of care for this patient population and many others are interested in doing so.² In order to provide clients with the opportunity to understand the care experience of their diverse patient populations, Press Ganey has developed a set of new variables regarding sex, gender identity, and sexual orientation designed to aid in this endeavor.

Building Quality Improvement in Health Care Equality

Federal departments, such as the U.S. Department of Health & Human Services (HHS), and its subsidiaries Health Resources & Services Administration (HRSA) and the Agency for Healthcare Research & Quality (AHRQ), support the effort to provide higher quality, meaningful care to the LGBTQI community through education, initiatives and grants. Non-governmental agencies (NGOs) are also working with healthcare organizations and providers in the field to provide support for QI efforts for this patient population. These organizations offer guidelines for and recognition of health care leaders through certification programs and as preferred providers for LGBTQI health care. Among them are the American Hospital Association (AHA); the Human Rights Campaign (HRC); Parents, Families, and Friends of Lesbians and Gays (PFLAG); and the Gay and Lesbian Medical Association. There are many resources available from these and other organizations. Several also offer awareness campaign materials and indexing opportunities.³

¹ More descriptive acronym exists: the letter A (Asexual). Recent article on the use of LGBTQI and additions to the acronym, see: <http://www.chicagotribune.com/lifestyles/sc-lgbtqia-letters-meaning-family-0606-20170602-story.html>

For definitions of these terms, go to:
<http://www.hrc.org/resources/glossary-of-terms>
<https://www.pflag.org/glossary>
<https://lgbtqia.ucdavis.edu/educated/glossary.html>

² See the following articles as primers to these issues:
a) 'Go Back To California': When Providers Fail Transgender Patients. Laura Arrowsmith. *Health Aff September 2017 vol. 36 no. 9 1679-1682.*

b) Treating LGBT Status as a Patient Safety Issue. Sally Deming, Julie Dooling, Lesley Kadlec, MA, Annessa Kirby & Megan Munns. *Journal of AHIMA 87, no. 4 (April 2016): 36-37.* <http://bok.ahima.org/doc?oid=301414#WejHLtSyUk>

³ #123forEquity Campaign to Eliminate Health Care Disparities
<http://www.equityofcare.org/>

New Variables and Variable Sets

The following variables are available for immediate use in all Patient Experience services lines. The demographic variables (see Table 1) are designed to respect the fluidity of the ways in which individuals consider themselves when thinking of sex, gender identity, and sexual orientation. The evaluative questions (see Tables 2-4) are designed to identify the patient experience of safety, comfort, and attention to special health care needs associated with the patient's sex, gender identity, and sexual orientation. All evaluative questions use the Press Ganey response scale. The design process included an exhaustive literature review regarding measures, social science theory about these constructs, and in-depth discussions with clients.

Table 1: Demographic Questions

Question	Response Categories
1. Does your gender identity differ from your gender assigned at birth?	Yes No
2. Which category best describes your sex?	Female Male Intersexed Transsexed Transitioning
3. With which gender do you currently most identify yourself?	Woman Man Transgender Man (Woman-to-Man) Transgender Woman (Man-to-Woman) Genderqueer (not exclusively a man nor a woman) Gender non-conforming Other Gender category Please feel free to specify (comment line): _____
4. Which category best describes your current sexual orientation?	Heterosexual/Straight Homosexual/Gay Homosexual/Lesbian Bisexual Other sexual orientation Please feel free to specify (comment line): _____

HRC Equality in Care Index -- having appropriate survey measures designed specifically to identify LGBTQ patient's experience of care is important to receiving the designation as a Leader in Health Equity, an important credential for organizations
<http://www.hrc.org/hei/leaders-in-lgbt-healthcare-equality>

Straight for Equality (a project of the PFLAG national organization)
<http://www.straightforequality.org/GLMADatabase>

Gay and Lesbian Medical Association
<http://www.glma.org/>

Table 2: Evaluative Questions regarding Patient Sex

Question
1. Extent to which you felt safe being treated at our facility with respect to your sex
2. Extent to which you felt comfortable being treated at our facility with respect to your sex
3. Staff worked to address any special healthcare needs due to your sex

Table 3: Evaluative Questions regarding Patient Gender Identity

Question
1. Extent to which you felt safe being treated at our facility with respect to your gender identity
2. Extent to which you felt comfortable being treated at our facility with respect to your gender identity
3. Staff worked to address any special healthcare needs due to your gender identity

Table 4: Evaluative Questions regarding Patient Sexual Orientation

Question
1. Extent to which you felt safe being treated at our facility with respect to your sexual orientation
2. Extent to which you felt comfortable being treated at our facility with respect to your sexual orientation
3. Staff worked to address any special healthcare needs due to your sexual orientation

Additional Recommendations

In addition to using the demographic variables and evaluative questions, in full or part, Press Ganey Research & Analytics Research Scientists (R&A) highly recommend adding the following item (see Table 5) to the Personal Issues section of all surveys in which these specialized measures are used if it is not already a part of the standard survey.

Question
1. Degree to which staff treated you with respect and dignity

In-House Preparation for Data Collection

Communication within organizations regarding the implementation of these variables is key to designing quality improvement projects that are developed based on the results of your survey efforts. In collaboration with clients, Press Ganey R&A has constructed the following brief protocol to aid in communicating about implementation, and the resulting analyses and reports and their use, to employees at all levels.⁴

1. Begin with Why: Educate Leaders, Care Providers and Staff on why your organization is collecting data concerning LGBTQI patients' experiences of care.

⁴ For a list of educational resources, contact your Advisor or Account Manager.

2. **Talk about Who:** Explain who is responsible for tracking the outcomes of the survey data, analyses, and reports, and deciding how the data should be disseminated.
3. **Share How:** Share the questions that your organization has chosen to include in the surveys and how they will appear. Explain how the data will be used to improve quality for this patient population in your organization.
4. **State When:** Share the date that the surveys with the new questions will begin to be disseminated to patients.
5. **Explain What:** Provide a mission/values/goal statement so that organization members are prepared to answer patient questions about why this information is being collected on patient experience surveys.

We at Press Ganey look forward to working with you and your organization to support the commitment to equal access and equitable, high quality healthcare for your diverse patient population. Contact your Patient Experience Advisor or Account Manager for further details.

Frequently Asked Questions

Are clients required to use the new demographic variables?

- Clients will achieve the best results in their analyses by having the cleanest data set possible from which to run comparisons and determine where quality improvement efforts need to occur. This is important to note as all existing demographic variables concerning sex, gender, and sexual orientation will be transformed into the new variables for analysis purposes. However, some variable response categories across the variables and databases in which they exist may be difficult to transform correctly. Therefore, Press Ganey recommends that clients utilize the new variables as these will be employed in reporting and analyses moving forward. Although not recommended, clients may use other variables if they feel these do not suit their needs.

Does a client need to use all of the demographic variables?

- As many of our question sets, these variables have been constructed to work together for both theoretical and methodological reasons. Question 1, does your gender identity differ from your gender assigned at birth, is part of an evidence-based lead-in strategy to help respondents transition into the question set and build rapport with the LGBTQI patient population with whom organizations aspire to build confidence with as healthcare providers. Questions 2-4 provide respondents a wide enough range of options to feel that their identities are respected but which limits the number of categories in order to avoid a cognitive burden for all respondents. They also provide clients with enough variability in the data to address patient experience concerns across a continuum of patient types. Although not recommended, clients may use a subset of the items, if they feel doing so better suits their patient's needs.

Does a client need to use all of the response categories for the demographic variables?

- The R&A strongly encourages using all of the response categories for each variable chosen to be employed. Not including all of the response options changes the meaning of the other response options and the perception of LGBTQI patients. Using all of the response options also provides the cleanest data as doing so will uphold the validity and reliability of the measure.

However, we cannot oblige clients to do so. If a client wishes not to use certain categories, R&A approval must be requested. If any other changes are requested to the response categories, R&A and Data Governance Committee approval is required.

Does a client need to use all of the evaluative questions?

- No. Clients may use the evaluative questions as they see fit in order to achieve their quality improvement goals. R&A recommends that clients either focus on one personal characteristic or one experience characteristic. For example, a client may be most interested in knowing if their staff provides a safe, comfortable, characteristic focused healthcare based on a patient's gender identity. Or they may wish to know if all patients feel safe based on their sex, gender identity, and sexual orientation. The use of only one question from one section is not recommended but a client may do so.

What if my organization doesn't know where to begin their journey in collecting data about patients who may experience differences in access to and quality of healthcare based on their sociodemographic background?

- An additional demographic question has been designed to assist clients in collecting baseline data on this important aspect of care. This style of question is known as a multi-pick response variable, which exists of a primary question, a follow-up statement or term, each with a Yes/No response option. It is available in all of the survey product databases.
 - Did the patient care staff respect your expressed needs in these areas:
 - Cultural
 - Religious
 - Sex
 - Gender identity
 - Sexual orientation
 - Race and/or Ethnicity
 - Age
 - Disability
 - Nationality
- Regardless of whether or not a client uses the background question above, or if they know which areas within which they would like an evaluative baseline for one of these constructs, the following single-line questions have also been added to the databases:
 - **How well staff respected your needs based on your...:**
 - Culture
 - Religious beliefs
 - Race or ethnicity
 - **Gender Identity**
 - **Sexual Orientation**
 - Age
 - Disability
 - Nationality
- Please note: Any changes to be made in survey designer or SCFs require R&A approval and are granted at the Product Specialist discretion (at the question or response level).



Data Dictionary Definitions

DEMOGRAPHIC CHARACTERISTIC	RETIRED	ADOPTED
Sex (PT_SEX)	Either of the two major forms of individuals that occur in the human species and that are distinguished respectively as female or male.	A person's biological sex as classified by a physician at birth or through genital surgical intervention and/or modification.
Gender Identity (PT_GEN)	A person's internal, deeply felt sense of being male or female (or something other or in between). A person's gender identity may or may not correspond with their sex.	A person's internal, deeply felt sense of being feminine, masculine, (or something in-between) influenced by cultural and social norms as well as individual behavioral, and psychological traits. A person's gender identity may or may not correspond with their sex or sexual orientation.
Sexual Orientation (PT_SOR)	A person's sexual identity in relation to the gender to which they are attracted	A person's inherent or immutable emotional, romantic or sexual attraction to others. A person's sexual orientation may or may not correspond with their sex or gender identity.

Response Category Definitions for Terms Used

DEMOGRAPHIC QUESTION	Term	Definition
Sex (PT_SEX)	Female	People who have only female genitals and XX chromosome pattern and/or are assigned female sex at birth.
	Male	People who have only male genitals and XY chromosome pattern and/or are assigned male sex at birth.
	Intersexed	There are many different intersex variations. Some intersex people have ambiguous genitalia or internal sex organs, such as a person with both ovarian and testicular tissues. Other intersex people have a combination of chromosomes

		that is different than XY (male) and XX (female), like XXY. And some people are born with what looks like totally male or totally female genitals, but their internal organs or hormones released during puberty don't match.
	Transsexed	Transsexed (or Transsexual) people who transition from one sex to another using medical treatment(s). A person born as a male can become recognizably female through the use of hormones and/or surgical procedures; and a person born as a female can become recognizably male. That said, transsexuals are unable to change their genetics and cannot acquire the reproductive abilities of the sex to which they transition.
	Transitioning	A person in the process of becoming transsexed but who has not completed medical treatment.
Gender Identity (PT_GEN)	Woman	A person who was born female whose sense of personal and gender identity corresponds with the characteristics and qualities that are traditionally ascribed to women (associated terms: feminine or cisgender or cis female).
	Man	A person who was born male whose sense of personal and gender identity corresponds with the characteristics and qualities that are traditionally ascribed to men (associated terms: masculine or cisgender or cis male).
	Transgender Man (Woman-to-Man)	A transgendered man is a person whose gender identity now, a boy/man, is different

		from the gender they were thought to be at birth, a girl/woman.
	Transgender Woman (Man-to-Woman)	A transgendered woman is a person whose gender identity now, a girl/woman, is different from the gender they were thought to be at birth, a boy/man.
	Genderqueer (not exclusively a man nor a woman)	A person who does not subscribe to conventional gender distinctions but identifies with neither, both, or a combination of gender identities.
	Gender non-conforming	Being gender non-conforming means a person does not conform to traditional gender norms of being a man or a woman. This can be expressed through speech patterns, styles of dress, hobbies, sports enjoyed that might be considered more "feminine" or "masculine" than is traditionally associated with their gender.
Sexual Orientation (PT_SOR)	Heterosexual/Straight	A person who has an inherent or immutable emotional, romantic or sexual attraction to those of the opposite sex.
	Homosexual/Gay	A person who has an inherent or immutable emotional, romantic or sexual attraction to those of the male sex.
	Homosexual/Lesbian	A person who has an inherent or immutable emotional, romantic or sexual attraction to those of the female sex.
	Bisexual	A person who has an inherent or immutable emotional, romantic or sexual attraction to those of the either the male or female sex.