



Published in final edited form as:

J Adolesc Health. 2009 September ; 45(3): 222–229. doi:10.1016/j.jadohealth.2009.01.009.

Healthcare Preferences of Lesbian, Gay, Bisexual, Transgender and Questioning Youth

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INTRODUCTION

Lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth appear to be at higher risk for certain adverse health outcomes such as HIV and other sexually transmitted diseases, substance use, depression and suicide. An analysis of the 1995 Massachusetts Youth Risk Behavior Survey demonstrated that youth who identified as homosexual or bisexual were twice as likely as heterosexual youth to ever have had sexual intercourse, and 2 ½ times as likely to have used alcohol or drugs at the last sexual episode, 5 five times as likely to have missed school because of safety concerns, 4 times as likely to have been threatened with a weapon at school, and 3 times as likely to have attempted suicide in the past year.ⁱ The American Academy of Pediatrics has published position papers underscoring and drawing providers' attention to the health needs of LGBTQ youth.ⁱⁱ

The Gay and Lesbian Medical Association recently summarized existing research substantiating the disparities in health and healthcare access for LGBT persons from a provider perspective.ⁱⁱⁱ However, little is known about experiences with healthcare providers and healthcare services from the youth's perspective.^{iv} Ginsburg et al were able to identify characteristics of healthcare providers and sites that affect care seeking, using both focus group and survey methodology with over 6000 ninth-graders in the Philadelphia school system.^v By allowing youth to participate in much of the development of the concepts and language of the survey, the authors were able to show that the participants were more concerned about provider characteristics than about setting or services.^{vi} The study's inferences were limited in that it included only in-school urban youth, and included no questions concerning sexual orientation, so no conclusions could be made about LGBTQ youth. Acknowledging this, Ginsburg et al surveyed 94 urban LGBTQ youth, ages 14–23 years, from local GLBT youth service agencies, and found that these youth prioritized clinician characteristics similar to the school-based sample: maintaining privacy, offering respect to youth, being well-educated, not talking down to patients, and being a good listener. The youth also prioritized clinician characteristics such as holding a nonjudgmental stance about LGBTQ persons as well as not assuming that every LGBTQ youth has HIV.^{vii}

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Our goal was identify preferences from a heterogeneous sample of LGBTQ youth with regard to healthcare providers, healthcare settings and health concerns they consider important to discuss with a healthcare provider. *Our null hypothesis was that there were no associations between age, gender and race/ethnicity and sexual orientation and the relative importance assigned by our sample of youth to specific provider/ setting characteristics and health concerns.*

METHODS

Sample

To include a heterogeneous group of LGBTQ youth, we placed the survey within an established Internet website, Youth Guardian Services (www.youth-guard.org), a youth-run, 501(c)(3) non-profit organization that provides support services on the Internet to LGBTQ and straight supportive youth through creating secure, age-specific e-mail groups, and by providing lists of resources, and links to other youth-supportive websites. The top ten search phrases or keywords for the YGS site include youth, gay, gay youth, schools, youth services, gay e-mail, gay e-mail list, gay mailing list, lesbian, and schools list. Among the top 10 web pages from which youth most frequently clicked a link to get to the YGS main page were www.google.com, search.yahoo.com, www.youth.org, safeschoolscoalition.org, www.elight.org, and www.alexsanchez.com. We hoped this methodology would also allow LGBTQ youth at varying stages of their affiliation and self-identification with the LGBT community to share their perspectives with us. Youth ages 13–21 years, the age interval used by the American Academy of Pediatrics to define adolescence, and who indicated they live in the U.S. or Canada were eligible for inclusion.

Consent and Confidentiality

Written consent from youth or parent/guardian was not required due to the anonymous nature of this internet-based survey, the minimal risk content of the survey, and because many LGBTQ youth may not have disclosed to parents/guardians. On the cover, respondents were informed that the purpose of the survey was to find out what youth ages 13 to 21 years old in the U.S. and Canada consider to be important qualities for healthcare providers and healthcare settings, and what concerns or problems youth consider to be important to discuss with healthcare providers. Youth were told that the information from this study would be used to inform and train healthcare providers on how to better serve youth. Youth were informed that the survey would be anonymous and that they would not be asked questions about their specific medical and mental health conditions. First name and e-mail address only were asked after the survey was completed and already imported separately into the database, and only if a respondent opted to participate in an optional lottery for a \$50 electronic gift certificate. No other identifying data were requested. Montefiore Medical Center's Institutional Review Board for the Protection of Human Subjects approved the study.

Questionnaire Design

We derived survey items from data collected from a series of four focus groups conducted in English with 37 LGBTQ youth facilitated by the investigators (NH and SS) at youth service agencies serving LGBTQ youth in New York City, Atlanta, Washington, DC, and Chicago. Based on the study by Ginsberg et al in the Philadelphia school system and on clinical experience, we developed three questions about healthcare providers and settings. Healthcare provider was defined on the questionnaire as physician, nurse practitioner, and physician assistant.

- What qualities are important to you in a healthcare provider?

- What qualities are important to you about the office or health center where you get healthcare?
- What concerns or problems are important to you to discuss with a healthcare provider?

For each question, we asked youth to generate a list of responses to each question on an index card. Using nominal group technique, a formally structured focus group approach to ensure equal participation by participants, each youth stated out loud an item on his/her list until one common list was created.^{viii} Youth reviewed the common list and decided together if certain items needed clarification and/or if certain items were duplicates and could be eliminated. Four groups were completed, at which point we noted that no new items had been introduced (saturation).^{ix} We organized the responses to each of the three questions, from all four groups, into one list of unduplicated items, with some editing for clarity of language. We added a Likert Scale (1–5), asking respondents to indicate the importance of each item with 1=Not at all important, 2=Somewhat important, 3=Important, 4=Very Important, and 5=Extremely important.

We created a questionnaire to precede the lists of health provider/setting qualities and health issues/concerns, to ascertain demographic variables such as age, gender, race/ethnicity, state residence, and education, socioeconomic status, and living situation. The questionnaire also included three measures of sexual orientation: attraction, identity and experience; one question about attendance at an LGBTQ-youth serving agency; and two health experience questions: having health insurance and timing of their last routine healthcare visit.

We pilot tested the survey twice: first in paper form with ten youth at a LGBTQ youth-serving agency in New York City to establish face validity, and then on the web-based version of the survey on the Youth Guardian Services website with three youth at desktop computers set up at a LGBT youth-serving agency in Atlanta. Based on feedback from the youth, some questions were deleted, adjustments were made in the sequence of some questions, and survey instructions were improved. Based on the final piloting, we estimated the survey would take 15 minutes to complete.

The survey was web-activated on July 23, 2002. On that date, electronic announcements were sent to the e-mail lists and websites of several youth-serving organizations. In addition, printed posters about the survey were posted at 27 LGBTQ youth-serving agencies around the United States, providing a URL that allowed youth to bypass the YGS main page and go directly to the survey. The survey remained active on the website for exactly one year.

Data Management/Statistical Issues

An Access database was derived, and the database checked for duplicates in an attempt to control for the possibility of respondents completing more than one survey. Survey respondents had been instructed not to complete more than one survey. In addition, feedback from youth during the pilot-testing phase indicated the survey length would be a disincentive to respond more than once. Given these measures, we were confident that multiple responses from individual subjects were minimized.

Younger age was defined as 13–17 years, with older as 18–21 years. Sexual orientation was defined as sexual attraction rather than sexual identity or sexual behavior because sexual attraction is considered to be a more stable aspect of sexual orientation.^x Also, sexual attraction is the sexual orientation variable used in the National Longitudinal Study of Adolescent Health (Add Health),^{xi} xii and in certain local versions of the Youth Risk Behavior Surveillance System (YRBSS).^{xiii} In contrast, sexual identity, and the language associated with it, are often determined by age, psychosocial development, and culture, and therefore are subject to change over time and groups. In terms of sexual behavior, 35% of respondents reported having had

no sexual experience in the last year. Thus, we decided that using sexual attraction would allow us to draw a more representative sample.

Descriptive statistics were derived on the demographic and healthcare experience items, and include relative frequencies for categorical variables. Because each of the healthcare provider/setting characteristics and health concern variables was measured along an ordinal scale, associations between these variables and demographic characteristics as well as sexual attraction were assessed for significance using Wilcoxon Rank Sum tests for dichotomous characteristics (e.g., attracted to opposite sex), Kruskal-Wallis tests for polychotomous characteristics (e.g., race), and Spearman Rank correlations for continuous variables. The median rank across respondents for an item's 1 to 5 Likert Scale was derived. The medians of these items were then ranked across items within each of the three parts of the questionnaire. Differences among individual item ranks were assessed using Friedman's Nonparametric Test; because this yields an overall test of differences only, a one-way analysis of variance with a Duncan's Multiple Range test was used as a guide to determine items with similar ranks (clusters). As a result, each of the item lists in the three questionnaire parts may have different numbers of ranks, as well as different numbers of items within each rank. Furthermore, all items that have the same ranking are considered to be equivalent and the order presented in the accompanying tables reflects only the original sequencing within the survey itself. Final ranks with lower values imply greater importance. For all hypothesis tests, results were considered significant for p-values less than 0.05. Analyses were performed using SAS Version 9.1.1.

RESULTS

A total of 788 youth responded to the web-based survey, with no duplicates noted. Of the respondents, 15 were excluded due to age outside of required range and 25 due to living outside the US or Canada. Nine were excluded due to missing age, and 10 due to missing location of residence (4 were missing both age and geographic location).

Of the 733 remaining (Table 1), the average age was 16.9 (SD= 2.2) years, and 84% were currently in school, with 5% out of school prior to achieving a high school diploma. 30% and 16% lived in suburban and rural settings, respectively. 25% of respondents lived in the Northeast United States, 18% in the Midwestern U.S., 25% in the Southern U.S., and 27% in the Western United States; 5% of respondents were living in Canada. 30% were non-white, and half were males. 41% had at least one parent with a college education. 5% reported an unstable living situation. 84% had health insurance. 74% reported that they had seen a healthcare provider within the last year. Only 24% reported attending an agency that provided services to LGBTQ-youth. 51% of these reported attending these agencies for less than one year. About two-thirds reported having had sexual experience in the last 12 months; no gender differences were noted. Less than 5% were attracted to the opposite sex only. 8% of females v. 1% of males were unsure about their sexual attraction ($p < .0001$).

Items regarding healthcare providers are ranked by importance in Table 2. In general, items in the highest ranking tend to describe provider qualities and interpersonal skills more than provider knowledge and experience. Provider qualities in the highest rankings (1-3, 1 being most important) include being respectful, honest, non-judgmental, supportive and friendly, and treating LGBTQ youth the same as other youth. Knowledge and Experience items among the higher rankings include being competent, educated about HIV transmission and prevention, educated about gay and lesbian health issues, experienced with working with youth, and knowing when consultation is necessary. Items in the lowest ranking include gender and sexual orientation of the provider.

Items regarding healthcare setting are ranked by importance (Table 3). Items regarding healthcare concerns and issues warranting discussion with a healthcare provider are ranked by importance (Table 4). In all three tables, items within a particular rank are ordered to reflect their original placement within the survey and are otherwise considered to be equivalent within the rank.

Some small but significant associations ($p < .01$) among the highest rankings were identified with regard to gender, race/ethnicity, age, and same-sex attraction. One significant association with gender was identified (we excluded transgender respondents (2%) from this analysis given small numbers). Females ranked as more important that the office/health center offers mental health services. Significant associations for race/ethnicity are as follows: African American youth ranked as more important that the office/health center provides care to youth only, and ranked as more important discussing with providers about sexual behavior, family problems, and future goals. One significant association with age was identified. Younger youth indicated as more important that the provider discusses concerns about talking with parents/family about being LGBTQ. Having the same-sex attraction was significantly associated with the following provider qualities: “makes me feel comfortable,” “is non-judgmental,” “treats LGBTQ youth the same as other youth.”

DISCUSSION

This study targeted an often hard to reach subpopulation of youth, with special health risks and special barriers to fully accessing healthcare services. The sample of LGBTQ youth is uniquely heterogeneous in three ways: 1) geographic diversity--across North America and both urban and non-urban settings; 2) affiliation diversity: one-fourth attended LGBTQ-youth serving agencies and three-fourths did not; and, 3) healthcare utilization diversity: three-fourths reported having had a routine healthcare visit within the last year, and one-fourth did not, notable for a sample not accessed directly from a health or social service agency. This study's methodology, by using the Internet to obtain subjects, specifically addressed a limitation of the Ginsburg study, which drew subjects solely from local, urban, social service agencies targeting LGBTQ youth.

Results indicate that interpersonal skills of providers and how they interact with patients were more important to youth than providers' specific competencies. Youth identified several concerns unique to their sexual orientation such as provider comfort, experience, knowledge and attitude about LGBTQ youth. Youth in this study ranked highest in importance that the provider treat LGBTQ youth the same as other youth. Of note, LGBTQ youth ranked gender and sexual orientation of the provider among the lowest in importance, suggesting that these youth do not necessarily need to be served only by LGBT health care providers or by health care providers of the same gender, nor do they need the health care provider to disclose sexual orientation. This finding also may have implications for further understanding of how cross-cultural interaction factors may be integral to the development of healthy relationships between providers and adolescent patients from diverse backgrounds.^{xiv} In addition, youth identified as important many concerns that are not unique to sexual orientation, such as provider overall competency and experience, insurance, and such office/health center qualities as cleanliness, accessibility in terms of hours, cost and ease of making appointments. Many of these are concerns that had been identified in both Ginsburg samples, suggesting that LGBTQ youth seem to be very similar to their non-LGBTQ peers in terms of what it important to them regarding a health care encounter.

Among the highest ranked health concerns are significant morbidities prevalent in youth in general, but more prevalent in LGBTQ youth, such as risky sexual behavior, depression and suicidal ideation, harassment or violence in the community or school, data consistent with the

Massachusetts YRBS study.^{xv} Additionally, these youth identified preventive healthcare, nutrition, and safe sex among the highest ranked health concerns. This suggests the importance for providers to not only address health risks, but to also emphasize wellness and health promotion. This sample of youth also cited family issues as important concerns to discuss with a healthcare provider, suggesting that providers should familiarize themselves with the psychosocial issues facing LGBTQ youth, thereby contextualizing these youth within the framework of home and family.

Few differences were noted between demographic subgroups. Of those that emerged, most were expected. For instance, young women ranked mental health services as more important than did young men, a finding consistent with the higher prevalence of depression among adolescent females than among adolescent males.^{xvi} Findings related to race/ethnicity underscore the need for greater cultural sensitivity to both ethnic and sexual identifications.^{xvii} Among concerns to be discussed with providers, younger youth ranked as more important talking with family about sexual orientation, possibly reflecting the fact that many LGBTQ youth are “coming out” earlier while still living at home with parents. Not unexpectedly, youth reporting same sex attractions emphasized the importance of feeling comfortable, of not being “judged,” and of being treated the same way as other youth are treated by providers.

Although one might be concerned about a potential bias in terms of socioeconomic status due to limiting creating access to the survey through the Internet, we found that parental educational attainment reported by this sample is consistent with that of the 2004 U.S. census^{xviii}. Internet access is increasing across socioeconomic groups^{xix}. Moreover, studies show that, even when unable to access the Internet at home, disadvantaged youth are able to access the Internet through school and library resources.^{xx} Limitations of this study, which are inherent in the use of the Internet as a means for respondents to access the survey, include the inability to validate inclusion/exclusion criteria and to assure the uniqueness of each respondent. We believe that each respondent is unique because we noted no duplicate questionnaires, and feedback from youth during the piloting process indicated that the survey’s length posed a disincentive to youth to participate more than once. Moreover, results based on published evidence were observed from these data, underscoring the methodology’s validity. We believe that for the purposes of this study, the ability to achieve a heterogeneous sample outweigh these limitations. Furthermore, the role of the Internet for health research purposes in accessing marginalized and otherwise hard to reach populations, especially LGBTQ youth, deserves continued consideration and attention.

An additional limitation is the survey being available only in English; this may have excluded youth with low English literacy. There may be some recall bias in that approximately 25% of youth had not seen a provider in the last year. However, questions asked do not refer to the provider they have seen, but rather what hypothetical qualities they consider important in a healthcare provider. And, another limitation is the low participation of transgender youth, limiting inference and ability to evaluate generalizability.^{xxii} The methodological issue regarding sub-classifications of gender may have been a possible barrier to participation. We included only two choices for transgender - Female to Male, and Male to Female, and limited gender choices in questions on attraction and sexual experience to three: male, female, male and female. Barriers to participation need to be explored further in order to engage transgender youth in health research.

Despite these limitations, our findings can be used to generate hypotheses for further research about the provision of healthcare services to LGBTQ youth accounting for age, race/ethnicity and sexual orientation. Our findings also support the need to develop and evaluate interventions that focus on LGBTQ youth wellness and health promotion, familial support, and LGBTQ

youth resiliency.^{xxiii} Also, given that many youth who have same-sex attractions do not self-identify as lesbian, gay or bisexual, it would be worthwhile to explore how the process of self-identification impacts on preferences regarding health providers and health services.

Equally important, these data can be used to inform provider-training initiatives and methodology to evaluate quality care to LGBTQ youth. Because LGBTQ youth often grow up feeling invisible in environments that do not help them develop language to discuss their sexuality, it is critical that healthcare providers be able to comfortably and skillfully initiate dialogue. Evidence suggests that providers more often do not take a comprehensive sexual history from their adolescent patients^{xxiv,xxv} Thus, training of healthcare providers needs to be a priority. Ozer et al have shown that provider self-efficacy to screen adolescents for health risk behaviors is significantly related to both provider self-report and adolescent patient report of preventive screening.^{xxvi} The same researchers also demonstrated that providers' participation in a training workshop focused on preventive screening could increase service delivery by trained providers.^{xxvii} Preferences identified by this sample of LGBTQ youth highlight the importance of providers acting sensitively to LGBTQ youth, being attuned to their unique health needs, but with the particular understanding that these youth deserve the same treatment and access to quality healthcare as all youth.

Acknowledgments

Jason Hungerford, Executive Director, Youth Guardian Services for his pro-bono work to transforming the study into a secure on-line questionnaire on the YGS website, an act of generosity consistent with his dedication to promoting the well-being of LGBT youth;

Dr. Hal Strelnick for his thoughtful and discerning review of the manuscript.

Supported by Grant from Bronx CREED, 1 P60 MD000514-01, National Center on Minority Health & Health Disparities

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Table 1

Demographic Information (N=733)

	n	%
Less than 18 years	477	65
Suburban or rural	342	47
African American	75	10
Hispanic	50	7
White	512	71
Other/Mixed	88	12
Female	335	46
Transgender	16	2
In-school currently	614	84
Some high school education or with high school degree AND < 18 years	368	78
Some college or with college degree AND 18 years or older	153	60
Father with college degree	188	26
Mother with college degree	216	30
Living with parents or other family	554	76
No permanent living situation/ homeless	24	3
Health insurance active	611	84
Last routine health visit: within 12 months	537	74
Attends LGBTQ-youth serving agency	165	24
No sexual experience in the last year	258	35
Females attracted to males only	15	4
Females attracted to females only	148	44
Females attracted to both genders	144	43
Females unsure about their attraction	26	8
Males attracted to males only	240	60
Males attracted to females only	7	2
Males attracted to both genders	94	24
Males unsure about their attraction	4	1

Table 2

Final Ranking of Health Care Provider Qualities

Item: <i>The provide</i> :	Rank	Sub-Category
is competent (that is, has good medical skills)	1	Knowledge/Experience
is respectful to me	1	Personal/Interpersonal
is honest with me	1	Personal/Interpersonal
listens to me	1	Personal/Interpersonal
treats gay, lesbian, bisexual and transgender youth the same as other youth	1	Personal/Inter Personal
makes me feel comfortable	1	Personal/Interpersonal
is non-judgmental	1	Personal/Interpersonal
is willing to refer me to another provider if they are not able to take care of all my health needs.	2	Knowledge/Experience
is educated about HIV transmission & prevention	2	Knowledge/Experience
is supportive of my total well being	2	Personal/Interpersonal
is friendly and personable	2	Personal/Interpersonal
helps me to make decisions about my health care	2	Personal/Interpersonal
explains everything to me in "plain language"	2	Personal/Interpersonal
knows when to consult with colleagues to get other information/opinions	2	Knowledge/Experience
is educated about gay and lesbian health issues	3	Knowledge/Experience
is experienced working with youth	3	Knowledge/Experience
is intellectually inquisitive	3	Personal/Interpersonal
does not rush during the visit	3	Personal/Interpersonal
has a good sense of humor	4	Personal/Interpersonal
has been working in the health field for a long time	4	Knowledge/Experience
is experienced working with gay, lesbian, bisexual youth	4	Knowledge/Experience
asks me about my ideas for what is wrong with my health	4	Personal/Interpersonal
uses gay-inclusive language during the interview and on forms I am asked to fill out at the visit	5	Personal/Interpersonal
is educated about transgender health issues	6	Knowledge/Experience
is the same gender as me	7	Personal/Interpersonal
is experienced working with transgender youth	7	Knowledge/Experience
has the same sexual orientation as I do	8	Personal/Interpersonal

The number of ranks here was determined by statistical clustering. The order of items within each particular rank reflects the original sequence within the survey, such that all items within each rank are otherwise considered to be equivalent.

Table 3**Final Ranking of Office or Health Center Qualities**

Item <i>The office/health center</i> :	Rank	Category
is clean	1	Environment and Accessibility
accepts my health insurance	1	Environment and Accessibility
has friendly staff	2	Environment and Accessibility
offers screening and treatment for sexually transmitted diseases	2	Available Services
allows me to come without my parent/guardian	2	Environment and Accessibility
offers HIV testing	2	Available Services
provides confidential care for minors (youth under age 18 years old)	2	Environment and Accessibility
has information about referrals to mental health providers experienced with LGBT youth	3	Available Services
has information about referrals to community agencies for LGBT youth	3	Available Services
allows the same provider to see me visit to visit	3	Environment and Accessibility
makes sure the provider sees me on-time	3	Environment and Accessibility
has an easy process for getting appointments	3	Environment and Accessibility
has a short waiting time to get appointments	3	Environment and Accessibility
offers mental health services	3	Available Services
offers support groups for youth	4	Available Services
offers gynecological care	4	Available Services
has evening hours available	4	Environment and Accessibility
is located near to where I live	4	Environment and Accessibility
has weekend hours available	4	Environment and Accessibility
asks for input from youth about programs/services	4	Environment and Accessibility
has a sliding fee scale for youth without insurance	4	Environment and Accessibility
advertises itself as "LGBT friendly"	5	Environment and Accessibility
displays magazines, health education posters/brochures/videos for youth	5	Environment and Accessibility
displays magazines, health education posters/brochures/videos for LGBT youth	5	Environment and Accessibility
has an e-mail address for correspondence	6	Environment and Accessibility
advertises itself as "transgender friendly"	6	Environment and Accessibility
plays good music in the waiting area	7	Environment and Accessibility
has a waiting area for youth	7	Environment and Accessibility
provides care to youth only	8	Environment and Accessibility

The number of ranks here was determined by statistical clustering. The order of items within each particular rank reflects the original sequence within the survey, such that all items within each rank are otherwise considered to be equivalent.

Table 4

Final Ranking of Health Concerns or Problems to Discuss With A Health Care Provider

Items	Rank	Category
Depression	1	Mental Health
Medication side effects	1	Physical Health
STDs	1	STDs
HIV/AIDS	1	STDs
Preventive health care (staying healthy)	1	Physical Health
STD treatment and transmission issues for partners	1	STDs
Suicidal feelings	1	Mental Health
Taking multiple medications (e.g. chronic illness)	1	Physical Health
Nutrition	1	Physical Health
Safe sex	1	Sexuality
Family problems	1	Mental Health
Risky or unsafe sexual behavior	1	Sexuality
Holistic and complementary treatments	2	Physical Health
Harassment or violence in the community	2	Other
Harassment or violence at school or work	2	Other
Drug use	2	Mental Health
Alcohol abuse	2	Mental Health
All sexual behavior	2	Sexuality
Partner/domestic violence	2	Other
Other gynecologic problems	2	Gyn/GU, Reproductive Health
Sexual relationships	2	Sexuality
Menstrual problems	2	Gyn/GU, Reproductive Health
Future goals in personal life	2	Other
Job safety (work-related injuries)	2	Other
Smoking	2	Mental Health
Sexual orientation	2	Sexuality
Having children/parenting options	2	Gyn/GU, Reproductive Health
Other male sexual health concerns	2	Gyn/GU, Reproductive Health
Testicular problems	2	Gyn/GU, Reproductive Health
Pregnancy prevention	2	Gyn/GU, Reproductive Health
Body piercing	2	Physical Health
Talking to parents/family about being LGBT	2	Sexuality
Tattooing	2	Physical Health
Sexual pleasure	3	Sexuality
Taking feminizing or masculinizing hormones	3	Gender Issues/Transgender
Being transgender	3	Gender Issues/Transgender
Masturbation	3	Sexuality
Talking to parents/family about being transgender	3	Gender Issues/Transgender

The number of ranks here was determined by statistical clustering. The order of items within each particular rank reflects the original sequence within the survey, such that all items within each rank are otherwise considered to be equivalent.