Trans Health in Cancer Genetic Counseling

Q46

Dear NSGC member,

My name is Tala Berro and I am a second-year genetic counseling student at Boston University. I am in search of genetic counselors in the Cancer Special Interest Group to participate in a research study for my capstone project (master's thesis). As a subscriber to the NSGC listserv, your opinions are valued.

Our study is about cancer genetic counselors' anticipated behaviors when counseling transgender patients. Study participation involves a brief web-based survey that is estimated to take 15 minutes. Responses to the survey are completely anonymous. Participation is voluntary and you can discontinue the survey at any time by exiting the web window.

As a thank you for your efforts, at the end of the study you will have the opportunity to enter a lottery for one of three $25 Amazon e-gift cards. All contact information necessary to enter the lottery will be collected in a separate webpage and will in no way be linked to your study. By continuing to the survey, you are consenting to be part of the study.

Any questions?

Please contact Tala Berro at [talab@bu.edu](mailto:talab@bu.edu)

Page Break

Q30 The following are definitions of terms combined from UCSF Center of Excellence for Transgender Health, GLAAD, and the National Center for Transgender Equality are listed at the bottom of each page of the survey. Please use as a reference.

**Cisgender:** A term used by some to describe people who are not transgender.

**Gender Expression:**How a person represents or expresses one’s gender identity to others, often through behavior, clothing, hairstyles, voice or body characteristics.

**Gender Identity:**An individual’s internal sense of being male, female, or something else. Since gender identity is internal, one’s gender identity is not necessarily visible to others. **LGBTQ:**Acronym for lesbian, gay, bisexual, transgender, queer/questioning, et cetera **Nonbinary/Genderqueer:**A term used by some individuals who identify as neither entirely male nor entirely female.

**Pronouns**: The pronoun or set of pronouns that a person identifies with and would like to be called when their proper name is not being used. Examples include “she/her/hers,” “he/him/his,” ze/hir/hirs,” and “they/them/theirs.”

**Queer:**A term used to refer to lesbian, gay, bisexual and, often also transgender, people. Some use queer as an alternative to "gay" in an effort to be more inclusive.

**Sex:**Historically has referred to the sex assigned at birth, based on assessment of external genitalia, as well as chromosomes and gonads.

**Sexual Orientation:**Describes sexual attraction only, and is not directly related to gender identity.

**Transgender (trans):**A term for people whose gender identity, expression or behavior is different from those typically associated with their assigned sex at birth. "Trans" is shorthand for "transgender." (Note: Transgender is correctly used as an adjective, not a noun.)

**Transgender Man:** A person who was assigned female at birth, but identifies and lives as a male (seen in some articles as “FTM”).

**Transgender Woman:** A person who was assigned male at birth, but identifies and lives as a female (seen in some articles as “MTF”).

**Gender Affirmation Therapy:** Various medical interventions including hormone therapy, surgery, facial hair removal, interventions for the modification of speech and communication, and behavioral adaptations such as genital tucking or packing, or chest binding that transgender people may choose to undergo in order to express their gender identity.

Page Break

Q1 Please rate how comfortable you are using these terms accurately.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Very uncomfortable: Would not use term (1) | Somewhat uncomfortable (2) | Unsure of meaning (3) | Somewhat comfortable (4) | Very comfortable: Would use term (5) |
| Cisgender (1) |  |  |  |  |  |
| Gender (2) |  |  |  |  |  |
| Gender Expression (3) |  |  |  |  |  |
| Gender Identity (4) |  |  |  |  |  |
| LGBTQ (5) |  |  |  |  |  |
| Nonbinary/Genderqueer (6) |  |  |  |  |  |
| Queer (7) |  |  |  |  |  |
| Sex (8) |  |  |  |  |  |
| Sexual Orientation (9) |  |  |  |  |  |
| Transgender (10) |  |  |  |  |  |
| Transgender Man (11) |  |  |  |  |  |
| Transgender Woman (12) |  |  |  |  |  |
| Gender Affirmation Therapy (13) |  |  |  |  |  |

Page Break

Q6 How confident would you feel counseling a trans patient on their cancer risk in your cancer clinic?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not confident at all (1) | Slightly confident (2) | Unsure (3) | Moderately Confident (4) | Very confident (5) |
| Counseling a trans patient (1) |  |  |  |  |  |

Page Break

Q40 How comfortable do you feel asking a trans patient or nonbinary patient the following:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Very uncomfortable (1) | Somewhat uncomfortable (2) | Unsure (3) | Somewhat comfortable (4) | Very comfortable (5) |
| Pronouns they use (she/her, he/him, they/them, zir, etc...) (1) |  |  |  |  |  |
| Hormone use (2) |  |  |  |  |  |
| Gender affirmation surgeries (3) |  |  |  |  |  |

Page Break

Q3 On average, what is your estimation of the number of patients you see each month?

* Less than 40 patients a month (1)
* Approximately 40 patients a month (2)
* More than 40 patients a month (3)

Q4 To your knowledge, have you seen any transgender patients in your practice in a cancer setting?

* Yes (1)
* No (2)
* Not Sure (3)

Display This Question:

If To your knowledge, have you seen any transgender patients in your practice in a cancer setting?&nbsp;<o:p></o:p> <span style="font-size:16px;"><span style="font-family:arial,helvetica,sans-serif;">Yes</span></span> Is Selected

Q5 Approximately, how many transgender patients have you seen?

* 1 (1)
* 2-5 (2)
* 6-10 (3)
* over 10 (4)

Page Break

Q47 The following questions will involve 7 case examples of patients who identify as transgender or nonbinary. Please answer based on your current knowledge and/or best assumption, without looking up information online.

Page Break

Q8 Case 1: A patient you see in clinic is a trans man. Please explain how you would draw this individual on a pedigree and why.

Q37 Case 2: A patient you see in clinic is a genderqueer individual who was born with XX chromosomes. Please explain how you would draw this on a pedigree and why.

Page Break

Q7 Case 3: Below is a possible case example of a trans patient in a cancer clinic. Please choose the option that is the most similar to the way you anticipate counseling in this session.

A 50-year-old trans woman is referred to genetic counseling due to a significant family history of prostate cancer. During the session, the patient informs you that she had a vaginoplasty and has undergone hormone replacement therapy for seven years. Other than a normal colonoscopy she recently had, she has had no cancer screening. Select all the topics that are relevant to this patient’s medical care and her gender affirmation:

* Assess for genetic cancer risks and coordinate appropriate testing (1)
* Discuss breast cancer screening (2)
* Counsel the patient about her 0% prostate cancer risk since the patient is biologically XX and therefore does not have a prostate (3)
* Counsel the patient about her minimal risk of prostate cancer because the prostate gland was removed during surgery (4)
* Counsel the patient about the need for prostate cancer screening since the prostate is still intact (5)
* Would not recommend any of the above (6)

Page Break

Q9 Case 4: Below is a possible case example of a trans patient in a cancer clinic. Please choose the option that is the most similar to the way you anticipate counseling in this session.

You meet with a 26-year-old trans woman who tests positive for a *BRCA1* mutation. The patient has not undergone any gender affirmation therapies or surgeries but has conveyed interest in doing so. Select all the topics that are relevant to this patient’s medical care and her gender affirmation:

* Hormone therapy to increase estrogen levels (1)
* Breast augmentation surgery options (2)
* Risk-reducing bilateral salpingo oophorectomy (3)
* Hormone therapy to increase testosterone levels (4)
* Risk-reducing bilateral mastectomy (5)
* Prostate cancer screening (6)
* Would not recommend any of the above (7)

Page Break

Q10 Case 5: Below is a possible case example of a trans patient in a cancer clinic. Please choose the option that is the most similar to the way you anticipate counseling in this session.

A 35-year-old trans man is referred to you due to his family history of a mother with colon cancer at age 40 and maternal uncle with stomach cancer at age 45. He is found to have Lynch syndrome. The patient has not undergone any gender affirmation therapies or surgeries but has conveyed his interest in doing so. Select all the topics that are relevant to this patient’s medical care and his gender affirmation:

* Colonoscopy (1)
* Upper Endoscopy (2)
* Risk-reducing hysterectomy (3)
* Risk-reducing bilateral salpingo oophorectomy (4)
* Hormone therapy to increase estrogen levels (5)
* Hormone therapy to increase testosterone levels (6)
* Would not recommend any of the above (7)

Page Break

Q35 Case 6: Below is a possible case example of a trans patient in a cancer clinic. Please choose the option that is the most similar to the way you anticipate counseling in this session.

A trans man *ATM* mutation carrier who has not had any gender affirmation therapies and his cisgender male partner, whom he is sexually active with, are seen by you in clinic to discuss his medical management. Select all the topics that you would discuss during the counseling session:

* Breast Cancer Risk (1)
* Pancreatic Cancer Risk (2)
* Estrogen Therapy (3)
* Risk to have a child with Ataxia Telangiectasia with current partner (4)
* Aromatase Inhibitor (5)
* Would not recommend any of the above (6)

Page Break

Q32 Case 7: Below is a possible case example of a trans patient in a cancer clinic. Please choose the option that is the most similar to the way you anticipate counseling in this session.

A 16-year-old trans girl is post-pubescent and is seeking gender affirmation therapy via estrogen therapy. She is referred to your clinic due to her mother having a *BRCA2* mutation.

* I would offer her genetic testing and if she was positive I would advise against estrogen therapy (1)
* I would offer her genetic testing and regardless of the result I would leave the decision about estrogen therapy up to her (2)
* I would not offer genetic testing, as she is a minor, and would advise against estrogen therapy (3)
* I would not offer genetic testing, as she is a minor, and would leave the decision about estrogen therapy up to her (4)
* I would not recommend any of the above (5)

Page Break

Q48 The following questions are focused on your genetic counseling practice and demographics as a genetic counselor.

Page Break

Q34 If a trans patient was referred to you for genetic counseling, would you counsel them or would you refer them to a different genetic counselor?

* Would counsel (1)
* Would refer because I do not feel equipped to assess cancer risk for a trans patient (2)
* Would refer because I do not feel comfortable treating a trans patient (3)

Q13 Do you have resources in your clinic for LGBTQ services?

* Yes (1)
* No (2)
* Not Sure (3)

Q14  Have you had any education or training specific to transgender health?

* Yes (1)
* No (2)

Display This Question:

If &nbsp;Have you had any education or training specific to transgender health? <o:p></o:p> <span style="font-size:16px;"><span style="font-family:arial,helvetica,sans-serif;">Yes</span></span> Is Selected

Q15 What type of education or training have you had specific to transgender health?

* Genetic Counseling Graduate Program (1)
* Conference (2)
* Workshops (3)
* Education Specific to trans health in cancer (4)
* Other (5) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q16 Would it be beneficial to your practice to have more education on transgender health implications to cancer?

* Yes (1)
* No (2)
* Not Sure (3)

Q43 The World Professional Association for Transgender Health (WPATH) recommends that providers take an anatomical inventory of the organs each individual patient has at any given point in time. For example, a list of organs could be recorded in a chart, and subsequently updated, for each individual patient at an appointment. Suggested organs would include: testes, prostate, breasts, vagina, cervix, uterus, ovaries.  Please indicate if you think this would be beneficial or not beneficial for your practice.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not beneficial at all (1) | Slightly beneficial (2) | Unsure (3) | Moderately Beneficial (4) | Very Beneficial (5) |
| Beneficial: Not Beneficial (1) |  |  |  |  |  |

Page Break

Q17 Please indicate your age.

Q18 Please indicate the year you graduated from your genetic counseling program.

Q19 How many years have you worked in a cancer setting? (years in clinic and/or research)

* 1-2 (1)
* 3-5 (2)
* 6-10 (3)
* Greater than 10 (4)

Page Break

Q20 Please indicate your sex assigned at birth.

* Male (1)
* Female (2)
* Decline to answer (3)

Q21 Please indicate your gender identity.

* Man (1)
* Woman (2)
* Trans Man (3)
* Trans Woman (4)
* Non-binary/Gender-queer (5)
* Decline to answer (6)
* Other (7) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q22 Please indicate your pronouns.

* He/Him/His (1)
* She/Her/Hers (2)
* They/Them/Theirs (3)
* Ze/Zim, Hir, or other neutral pronouns (4)
* Other (5) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q23 Please indicate your sexual orientation.

* Heterosexual (straight) (1)
* Homosexual (gay/lesbian) (2)
* Bisexual (3)
* Queer (4)
* Decline to answer (5)
* Questioning (6)
* Other (7) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Page Break

Q12 Do you have family and/or friends who identify as transgender, nonbinary, or genderqueer?

* Yes (1)
* No (2)
* Not Sure (3)

Page Break

Q25 Please indicate the region in which you practice.

* CT,MA,ME,NH,RI,VT,CN Maritime Provinces (1)
* DC,DE,MD,NJ,NY,PA,VA,WV,PR,VI,Quebec (2)
* AL,FL,GA,KY,LA,MS,NC,SC,TN (3)
* AR,IA,IL,IN,KS,MI,MN,MO,ND,NE,OH,OK,SD,WI,Ontario (4)
* AZ,CO,MT,NM,TX,UT,WY,Alberta, Manitoba, Sask. (5)
* AK,CA,HI,ID,NV,OR,WA,British Columbia (6)
* Non-U.S. (7)

Q26 Please indicate the type of hospital in which you practice.

* Academic Medical Center (1)
* Public Hospital (2)
* Private Hospital (3)
* Academic or Commercial Diagnostic Laboratories (4)
* Community Health Center (5)
* Religious affiliated institution (6)
* Other (7)

Q24 Please indicate your race.

* White or Caucasian (1)
* Asian (2)
* Asian Indian (3)
* Black or African American (4)
* Other (5)
* American Indian or Alaskan Native (6)
* Native Hawaiian or Other Pacific Islander (7)

Q49 Please indicate your ethnicity.

* Hispanic (1)
* Not Hispanic (2)

Page Break

Q42 Thank you for completing the survey.

If you are interested in learning more about transgender health and implications for cancer risk assessment, please refer to:

UCSF Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People (<http://transhealth.ucsf.edu/protocols>)

If you are interested in more resources about transgender health in general, please refer to:

The National LGBT Health Education Center (<https://www.lgbthealtheducation.org/>)

Q50 As a thank you for your efforts, you have the option of entering a lottery for one of three $25 Amazon e-gift cards. All contact information necessary to enter the lottery will be collected in a separate webpage and will in no way be linked to your study.

Please click [here](https://docs.google.com/forms/d/e/1FAIpQLSchR6lRCWLwtEmdnm9z4DZMPbK6rBbFK_sxfNnzVnPv0lSRsA/viewform?usp=sf_link) if you would like to enter the lottery.

End of Block