



# LGBT PATIENT-CENTERED OUTCOMES

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Cancer survivors teach us how to improve care for all

LIZ MARGOLIES, NFN SCOUT



Margolies L, Scout NFN. *LGBT Patient-Centered Outcomes: Cancer Survivors Teach Us How To Improve Care For All*. April 2013. Online report available at: [www.cancer-network.org/patient\\_centered\\_outcomes](http://www.cancer-network.org/patient_centered_outcomes)



The National LGBT Cancer Network addresses the needs of LGBT people with cancer and those at risk by *educating* the LGBT community about their increased cancer risks, *training* healthcare providers to offer more culturally safe and welcoming care to LGBT patients, and *advocating* for LGBT inclusion in national cancer organizations, research, and media. The National LGBT Cancer Network conducted this study in conjunction with Dr. Marilyn Stoner, Assistant Professor of Nursing at California State University, San Bernadino. Dr. Stoner was the Principal Investigator for the study. Study funding was provided by The DAISY Foundation's J. Patrick Barnes Grant for Nursing Research and Evidence-Based Practice Projects ([DAISYfoundation.org](http://DAISYfoundation.org)). The development of this report was conceived and managed by the National LGBT Cancer Network.



The Network for LGBT Health Equity is a community-driven network of advocates and professionals looking to enhance LGBT health by eliminating tobacco use and other health disparities within our communities. We are one of six CDC-funded tobacco disparity networks and a project of The Fenway Institute in Boston. The Network advances these issues primarily by linking people and information to advance policy change. The Network for LGBT Health Equity provided technical assistance on the development of this educational report.

#### SPONSORS



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#### DEDICATION

This book is dedicated to the memory of Sister Bubbles Jewcee Fruit, a beloved member of the L.A. Sisters of Perpetual Indulgence who died of throat cancer in 2012. The Sisters are a 501(c)3 family, committed to social activism, social service and spiritual development.

# Introduction

The diagnosis of cancer is the beginning of a frightening and stressful period in anyone's life. The newly-diagnosed patient is suddenly embroiled in a calculus of medical decisions. As cancer treatment is pursued, they might see more health providers in a week than many friends will see in a decade. The extreme health event of a cancer diagnoses quickly molds average people into experts in the strengths and weaknesses of the healthcare system.

For many LGBT people, the critical questions about treatment options and recovery are followed immediately by concerns about social stigma. The all-important question of "Will I be healthy?" is compounded by an additional slew of worries. New questions such as "Should I come out to my doctor?" "Will I be safe if I do?" "Will my chosen family be welcome?" and "Will I be offered the information I need to know to take care of my relationship, my sexuality, my fertility, and my family?" are thrust into the forefront.

An increasing body of research suggests that these questions are related to health outcomes. Patient assessments of the

quality of their own healthcare are more predictive of health outcomes than provider ratings. Importantly, those that are the most satisfied with their healthcare tend to *stay* healthier. These findings have led to a new movement in healthcare, moving from "what's the matter" with patients to "what matters" to patients.<sup>1</sup> We describe this approach as "patient-centered care."

Shifting to patient-centered care represents not only healthier people but also a large potential cost savings to our healthcare system. As a result, there is a large investment into researching "what matters" to patients. In 2013, an estimated \$320 million of new funding will be dedicated to researching how to improve patient-centered outcomes in the U.S.<sup>2</sup>

Despite a long history of documenting LGBT health disparities, little is known about "what matters" to this community with regard to healthcare. Like many others, members of the LGBT community often think of the health system in the old model, where *good care* is solely defined

by *good medical decisions*. In the new patient-centered care model, how patients *feel* about medical decisions as well as a perception of *equitable treatment by providers* blends together to create the best possible health outcomes. Exploring the factors in this larger model might help explain the history of worse health outcomes experienced by the LGBT community.

LGBT cancer survivors are one such population that reports poorer health outcomes than their non-LGBT counterparts.<sup>3-5</sup> This fact, combined with the intense interactions cancer survivors have with the healthcare system, makes exploring the insights of these survivors particularly fertile ground to advance both patient-centered care as well as LGBT health.

In the following pages we present the responses of a survey of 311 LGBT cancer survivors as they describe what they would want healthcare providers to know about their experiences. Some of their stories show great strengths in our healthcare system. Some expose weaknesses. Taken as a whole, their words provide us with a roadmap of how to improve LGBT patient-centered outcomes. Not just for cancer care, but across all health disciplines.

We wish to thank all of the survivors who had the courage to speak up honestly about their experiences. By the very nature of this study, it is likely some of the voices on the pages that follow have now been silenced. Let us honor those lives by using all the lessons here to build lasting change.

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AT THE FENWAY INSTITUTE

1. <http://healthaffairs.org/blog/2012/01/24/patient-centered-care-what-it-means-and-how-to-get-there/>

2. <http://www.pcori.org/how-were-funded/>

3. Boehmer, U., Miao, X. and Ozonoff, A. (2011), Cancer survivorship and sexual orientation. *Cancer*. 117: 3796-3804. doi: 10.1002/cncr.25950

4. Hart, S., Coon, D., Kowalkowski, M., & Latini, D. (2011). 163 Gay Men with Prostate Cancer Report Significantly Worse HRQOL Than Heterosexual Men. *The Journal of Urology*. 185(4), e68-e69

5. Kleinmann, N. et al. *Nat. Rev. Urol.* 9, 258-265 (2012); published online 10 April 2012; doi:10.1038/nrurol.2012.56

# Methodology

The purpose of this study was to conduct pilot research into understanding the experience of being diagnosed with cancer by gay, lesbian, bisexual, and transgender patients. The study was approved by the Institutional Review Board of California State University, San Bernardino. M. Smith-Stoner was the principal investigator. The study is a correlational online 28-question survey. The

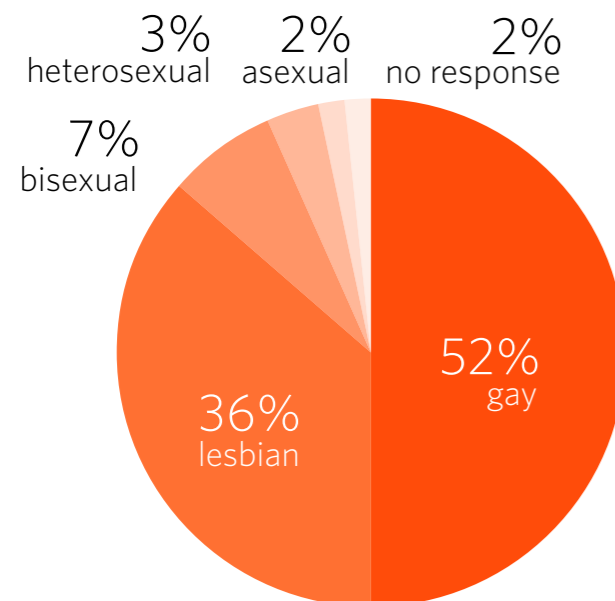
survey instrument was researcher designed based on a holistic model of comfort, intended to explore the physical, spiritual, environmental, and sociocultural domains of the human experience related to illness. To obtain participants, the online survey was widely advertised in LGBT-specific websites including blogs, newsletters, and other digital media. Inclusion criteria were that the

participant self identified as LGBT and had been diagnosed with cancer. Overall, 311 responses were obtained. All demographic questions were framed as “at the time of diagnosis”. Of the total respondents: 156 participants (52%) reported their sexual orientation as gay, 113 participants (36%) reported as lesbian, 22 participants (7%) reported as bisexual, 10 participants (3%) reported as heterosexual, 5 (2%) reported as asexual, and 5 participants (2%) did not report their sexual orientation. (Figure 1.) Of the respondents who reported a sex/gender: 165 reported male, 131 female, and 10 transgender. (Figure 2.) The fact that the survey did not allow distinct reporting of being transgender *and* male or female is a weakness of the study design and likely suppresses the total identifiable transgender

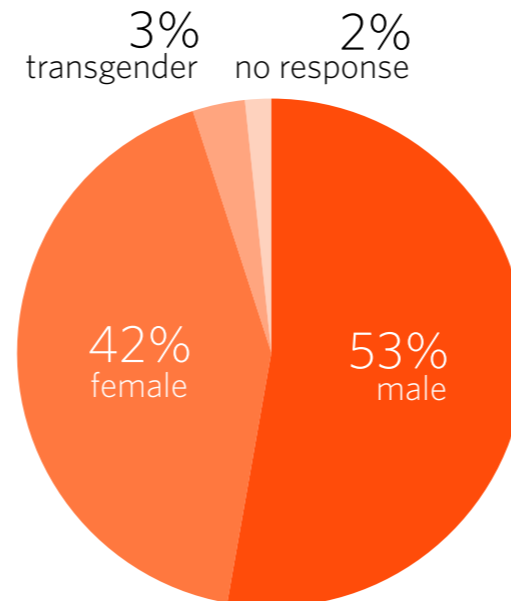
respondents. Of the participants who reported a race/ethnicity: 91% were white/caucasian and 9% were people of color. (Figure 3.) This is a distinct variance from the total population profile, and likely represents a weakness in the study outreach strategies. Of participants who reported where they lived: 263 participants (85%) lived in the United States and 38 participants (12%) lived outside of the United States. A map of the geographical range of the mainland U.S. respondents is presented on the next page. (Figure 4.)

Qualitative analysis, coding, and data reduction for this report were accomplished through two different daylong sessions of open coding between L. Margolies and NFN Scout, based exclusively on responses to an optional question at the end of the

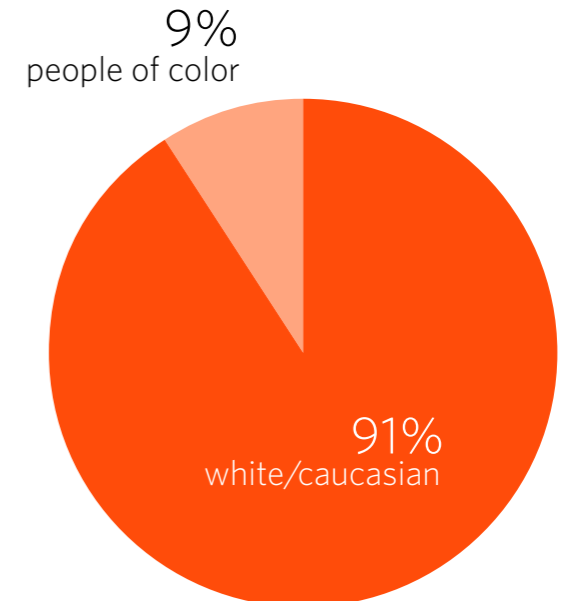
**FIGURE 1.** Sexual orientation



**FIGURE 2.** Sex/gender



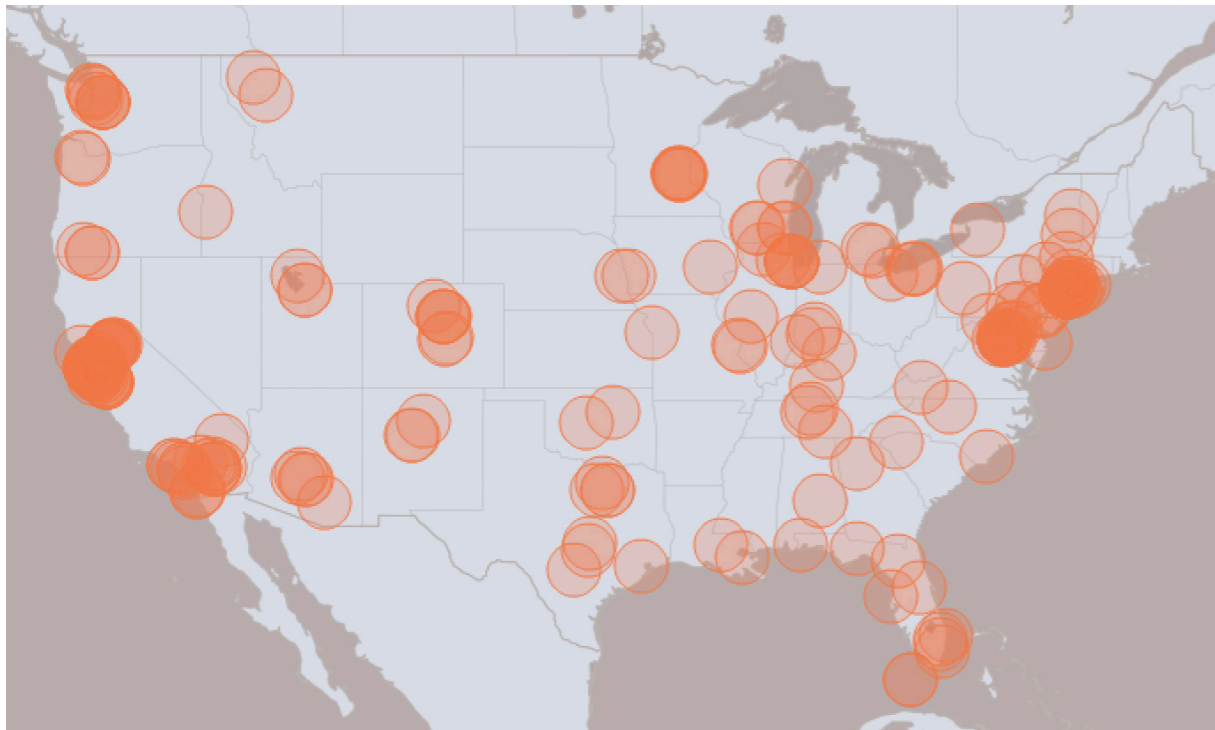
**FIGURE 3.** Race



survey, asking, “If you were to give a class to healthcare workers, focused on cancer care, what would you tell them about being LGBT and being diagnosed with cancer?” Of the 311 participants, 256 chose to respond. Qualitative analysis software was not used to analyze these responses; the quotes were printed out, cut up by hand, and sorted into categories. While the a priori framework of health determinants was kept in mind, the immersion in the data and discussion between Margolies and Scout guided the development of coding nodes. From this process the six major nodes presented here emerged. As coding continued, subcategories were identified for these major nodes, until distinct data were placed into subcategories

as was applicable. In the case of repetitive quotes, those thought to best highlight an issue were retained. Unclear quotes were discarded. Participant quotes were edited for grammar or brevity as indicated, or if needed, split to be presented under different applicable categories. Scout and Margolies then added brief explanatory paragraphs to introduce each node. Margolies took the lead on creating draft recommendations from the nodes and subcategories. Scout reviewed and edited these recommendations. Both drew from their long history conducting provider trainings to identify best practices. The resultant findings form the substance of this report.

**FIGURE 4.** Geographic distribution of respondents in the continental United States



## Other Survey Findings

The following charts and tables illustrate participant responses to 4 of the 28 survey questions. For each question, participants could choose more than one answer. The data serve as grounding to the themes discussed throughout the remainder of the book.

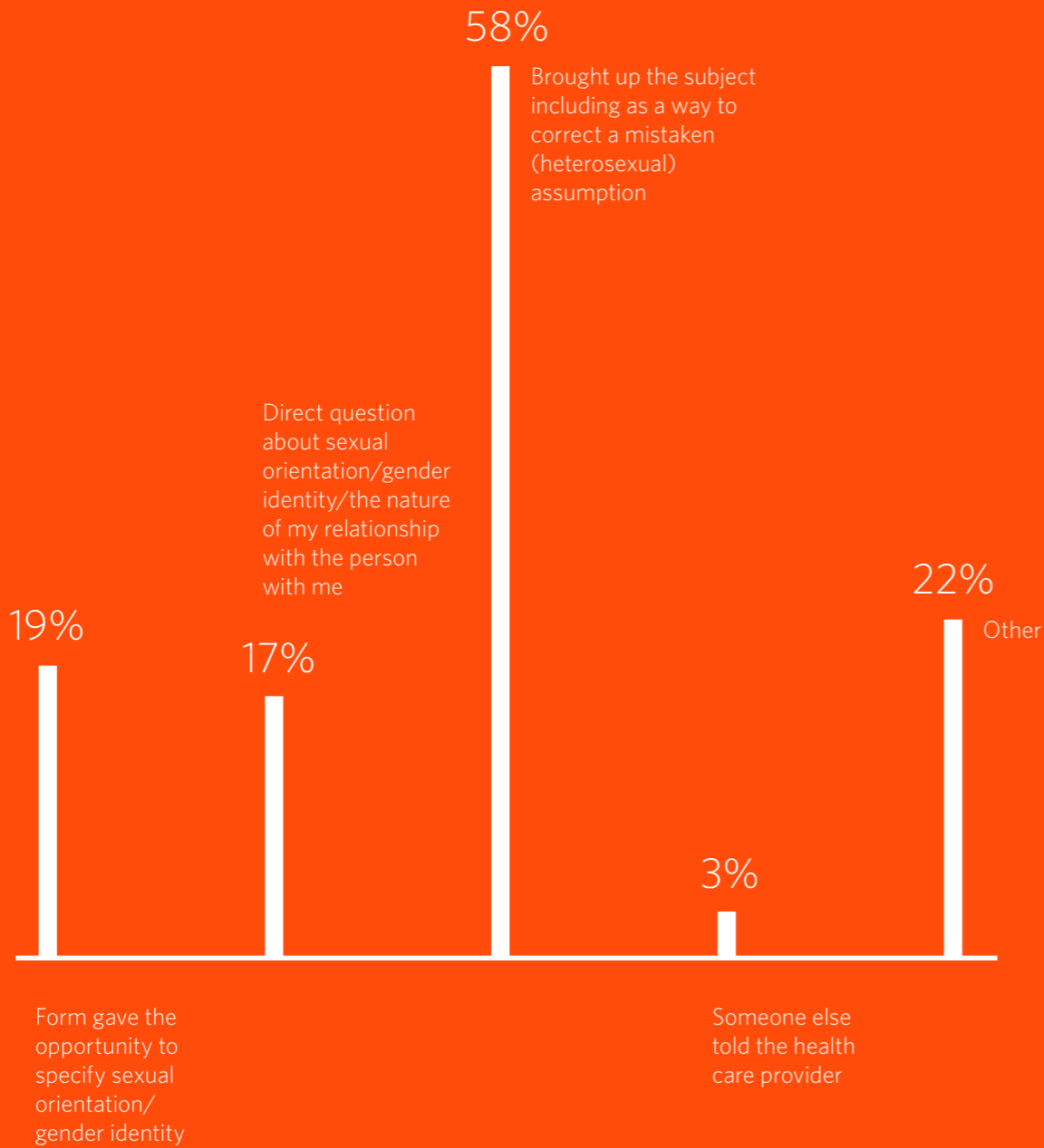
**SURVEY QUESTION:** Which of the following people knew about your gender identity and/or sexual orientation at the time of diagnosis?

88%	My primary care physician
57%	My surgeon
55%	My oncologist
52%	One or more of the nurses
41%	One or more of the clerical staff/receptionists
21%	My radiologist
17%	My social worker

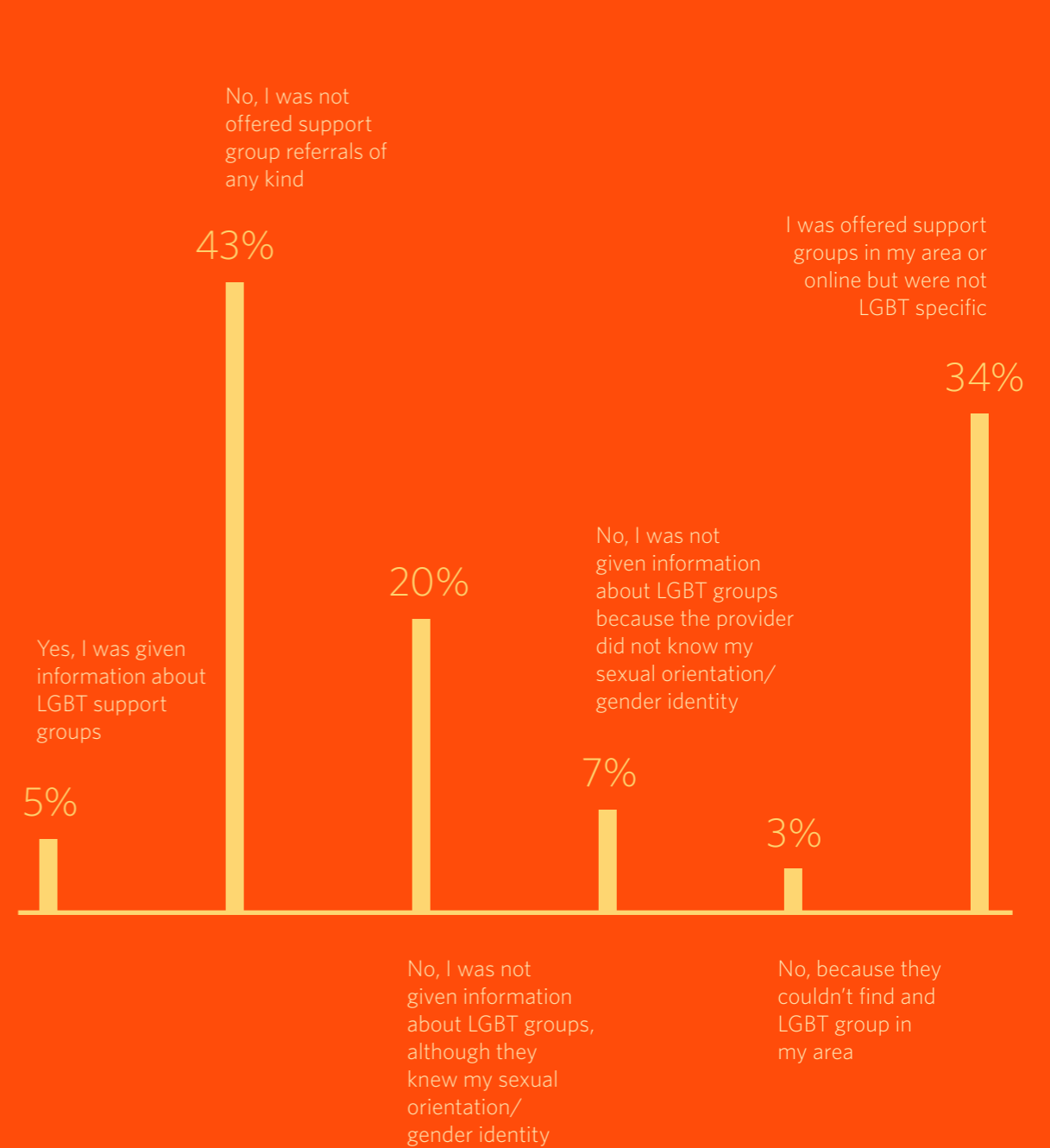
**SURVEY QUESTION:** Who did you consider to be part of your personal emotional support team at the time of diagnosis?

77%	Friends
62%	My partner at the time
40%	One or more of my parents
40%	One or more of my siblings
30%	One or more of my work colleagues
28%	Other family members
17%	Other
16%	One or more of my ex partners

**SURVEY QUESTION:** If you were out to anyone on your health team, how did that happen?



**SURVEY QUESTION:** Were you offered referrals to LGBT support groups for either survivors or caregivers?



# Study Findings

TO OBTAIN THIS STUDY'S INSIGHTS, WE ASKED LGBT CANCER SURVIVORS ONE QUESTION:



If you were to give a class to healthcare workers, focused on cancer care, what would you tell them about being LGBT and being diagnosed with cancer?

# 1

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## Stigma plays a prominent role in LGBT healthcare

Many LGBT people have a history of delaying or avoiding check ups and cancer screenings due to previous negative experiences in healthcare and/or feared discrimination.<sup>6</sup> Once diagnosed with cancer, LGBT people are thrust into the medical system. As a result, many LGBT cancer patients begin their treatment experience with more fear and wariness than other patients.

6. Harris Interactive Poll. "New National Survey Shows Top Causes for Delay by Lesbians in Obtaining Health Care." Rochester, NY: Harris, March 11, 2005. Online:[http://www.mautnerproject.org/programs\\_and\\_services/research/305.cfm](http://www.mautnerproject.org/programs_and_services/research/305.cfm)



## Stigma plays a prominent role in LGBT healthcare

### LGBT people are wary of the healthcare system, leading to increased feelings of vulnerability and stress

- “Although my doctor knew all about me, each encounter with new people—with blood draws, ultrasound, breast x-ray, etc.—had the basic anxiety of the procedure and layered on to that, the possibility of homophobia and having to watch out for myself.
- “Being LGBT can add additional stress to the whole cancer experience: feeling like things can’t be shared in general cancer support groups, misunderstandings among medical providers about roles of family members, existing strains in biological families due to coming out, partner issues during cancer care, etc.
- “When we are treated with hostility and denied care it adds a huge additional burden to the trauma of being diagnosed with cancer.
- “Healthcare providers also need to be aware that homophobia and the closet are the biggest obstacles to LGBT healthcare. Many don’t go because of homophobia they’ve experienced from doctors, or they don’t get the proper care because they can’t disclose that they’re LGBT (which might figure into a diagnosis).

## Recommendations

- ✓ **Providers and healthcare management should take additional steps to become educated about the stigma-related stress many LGBT people carry into treatment & strategies to reduce such stress**
  - Provide cultural competency training
  - Include LGBT leaders on community advisory bodies

# 2

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## **The local healthcare environment determines one's experience and is highly variable**

Like politics, all healthcare is local. Most patients are treated in medical centers near their homes and their cancer experience is determined by the unique staff they interact with there, as well as the policies of that institution, and the laws of their state. Treatment centers vary widely and experiences can be further complicated if an LGBT person is a member of multiple stigmatized populations, such as the undocumented or LGBT people of color. Overall, very few people can gauge if they are walking into a "safe" healthcare environment and fewer still have the option of changing if it proves perilous.

## The local healthcare environment determines one's experience and is highly variable

### Human interactions define the environment

” “Treatments for cancer are invasive and can be lethal, so patient trust in the providers who give these services is paramount.”

### Location can affect the reception

” “I have since learned other close LGBT friends...had similar [negative] experiences and we all now have to travel 40 miles to see the next closest endocrinologist.”

” “In a conservative area, I was not comfortable revealing [my sexual orientation] to my healthcare providers, even though I am 'out' to family and friends.”

” “We live in New York City—in a very gay neighborhood and my treatment was at a very 'gay hospital.' Being an out lesbian in a serious monogamous relationship was not particularly an issue nor was the presence of my partner in the hospital or during my treatment.”

### LGBT people may fear intolerance in religious institutions

” “My partner did not come to the hospital because the only good hospital around was a Catholic hospital and I didn't want my treatment compromised by them finding out about my 'sinful lifestyle.'”

” “I'm receiving my care through a religious institution and wouldn't want that to affect my care. I would want to teach tolerance so people like me aren't afraid to be open about their orientation. I shouldn't have to be afraid to say I'm queer just because of the religious leanings of the facility I'm at.”

### Provider cultural competency training helps with patient comfort

” “There are still doctors and others of different cultural and religious backgrounds that have negative feelings towards LGBT individuals. As a result, it is very difficult to openly discuss one's sexual orientation for fear of rejection and non-interest in one's health matters.”

## Recommendations

### ✓ Healthcare institutions and offices should actively convey that LGBT-welcoming behavior is a core expectation of all staff

- Include mandatory staff training
- Reinforce such welcome through the actions of management and public relations staff. For example, an article could be written on LGBT diversity for an employee newsletter
- Develop an LGBT study group

### ✓ Healthcare institutions and offices should convey a zero-tolerance environment for any discriminatory behavior on the part of staff

- Include scenarios and possible responses in annual staff trainings

### ✓ Healthcare institutions and offices need to broadcast their LGBT-welcoming policies and training to potential and current patients

- Include LGBT measures and nondiscrimination protections on intake forms
- Prominently display LGBT protections/welcome on website and in waiting rooms
- Partner with local LGBT community based organizations for public events, in public materials
- Tailor ads to LGBT media outlets
- Participate in and display the results from the Human Rights Campaign Healthcare Equality Index report card

## The local healthcare environment determines one's experience and is highly variable

” Perhaps include some sensitivity training for those who are not familiar with same-sex relationships to help those people who really want to say and do the right things but don't know how.”

### Inclusive forms and surveys help convey respect

” [Practitioners] need to ask their patient if they identify as LGBT or straight...They MUST include the patient's partner and family of choice in discussions, meetings, decisions. Include a box/question on the patient intake form that is inclusive.”

” If you know a nurse will be yelling out patient names in the waiting room, perhaps on the sign in form have a space for 'preferred name.'”

” For prostate cancer: questionnaires that discuss and rate sexual function in terms “of vaginal sex are not appropriate.”

### LGBT people often scan for cues of welcome/discrimination

” If a healthcare worker suspects a person is gay, or if they know a person is gay...they should be open about being supportive so the gay person does not live in constant fear of not being treated completely. It would be nice if those people wore pins or something identifying themselves so it is not an awkward conversation. I would love to see a sticker on the door of the office 'LGBT safe zone.'”

### Laws also help determine the environment

” I can only imagine how that loneliness and feeling of being “other” would have been compounded if I wasn't out as a lesbian, if I didn't feel safe to talk about who I was, if I didn't have some of the privilege I have, and if I didn't live in a state that allowed same-sex marriage.”

” ...Be more sensitive to my fright, my orientation and the consequences of DOMA and all the paperwork I had to put in place to protect my rights.”

## Recommendations

✓ **It is particularly important for LGBT-welcoming policies and training to be broadcast to the public in situations where there's greater historic stigma, such as in religious institutions, or regions with no LGBT civil rights protections**

✓ **Cultivate the safety of LGBT employees to be out at the workplace**

- Sponsor an LGBT employee group
- Include LGBT status on employee satisfaction surveys; ask about safety and being out at work

# 3

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## **Disclosure is often related to perceived safety**

Patients fare better when they can bring their whole self into treatment and have their caregivers by their sides. Conversely, when LGBT people feel that they must hide their identities and support system, the stress of cancer treatment is magnified, negatively impacting health outcomes.

Most of the survivors in our study repeatedly weighed this stress against their fear of substandard care or outright rejection. Some chose to stay in the closet during treatment, even if they were out in most other parts of their lives; a life threatening illness tipped the scales. Others were brave and changed providers when they sensed discrimination. Support structures were influential; our study found that LGBT survivors with partners were twice as likely to come out. Our research also showed that while 88% were out to their primary care physicians, they were more closeted during cancer treatment. In addition, many respondents wrote about the stress of repeatedly having to decide whether to come out or not to each member of their healthcare team.

## Disclosure is often related to perceived safety

### Coming out isn't a one time event

- ” “We never knew what to expect from health care providers at different levels and so were always bracing ourselves for some kind of difficulty or rejection.”
- ” “I am comfortable being out as a lesbian. Yet there are settings in which there is that situation of asking myself, do I want to have this discussion today, with this person, does it matter??? I bring it up when it seems to matter to the situation and the opportunity is available. Sometimes the process of coming out over and over is tiresome. Chemo Treatment and recovery from surgery is a full time job...it is a matter of cost/benefit analysis.”

### Staying in the closet is safer for some

- ” “As an alone, aging senior, I am also dealing with fear of rejection by being 'out' even though I was very 'out' when younger and in a partnership. There is a big part of the 'cancer' experience that never gets shared with the care givers or service providers when you are not comfortable letting them know who you really are!”
- ” “Healthcare providers need to understand that some LGBT people really are in danger of losing their livelihood and family if they're outed, so if a patient confides this to a provider, the provider needs to respect that and work with the patient to get him/her information about LGBT-friendly support networks in such a way that the patient's identity is not compromised. It's a difficult balance, but that's the reality.”
- ” “As an LGBT person receiving chemotherapy and radiation, I was afraid to reveal anything about my orientation as cancer treatment is literally life-and-death. In a conservative area, I was not comfortable revealing this information to my healthcare providers, even though I am 'out' to family and friends.”

## Recommendations

- ✓ **Collect evidence to see if LGBT patients feel safe coming out at your institution and use evidence to build safety**
  - Ask about LGBT status on patient satisfaction surveys
  - Ask about LGBT status on employee surveys and their relative safety
  - Convene LGBT employees as an advisory body, to suggest steps to increase patient safety
  - Include LGBT leaders on community advisory bodies to provide a constant source of feedback
  - Conduct an environmental scan of the facility to check how and when safety is conveyed to LGBT patients

## Disclosure is often related to perceived safety

### Many expressed fear of substandard care if they came out

- “I was never out during the whole process to anyone. I had no one in the hospital or doctor visit with me for fear of my gayness being discovered and then the doctors ‘accidentally’ not removing all the cancer lesions.”
- “An anti-gay surgeon could easily ‘accidentally’ miss one of the many small lesions of the cancer or not take out an infected lymph node. An anti-gay nurse could take longer to give pain medicine. Being discovered as a lesbian in a Catholic hospital can be lethal when having cancer.”

### The fears of substandard care may be warranted

- “As soon as my PCP found out I was gay, he became less attentive to my complaints, less supportive and aloof.”
- “[When the doctor] asked about my wedding band I explained that I was in a long-term relationship with my partner of 14 years. The look on his face, told me that he was recoiling from that knowledge...After my treatments were over I had gone back to him for to continue with my diabetes treatment and was told by the doctor that he could no longer treat me...”
- “I had an...assessment at a general practitioner/family physician, who made what seemed to me to be disparaging remarks about anal sex, saying curtly, ‘you shouldn’t put things up there that don’t belong.’”

## Disclosure is often related to perceived safety

### Some respondents addressed substandard care by changing doctors

”After being denied care by the initial breast surgeon I consulted, I had to transfer my case to another provider to obtain surgery. Subsequently the first medical oncologist I consulted after mastectomy also refused to offer chemotherapy...I privately questioned his oncology fellow who confirmed that he had considerable antipathy toward me because I am transgender, so I had to transfer my case a second time to yet another facility to obtain appropriate treatment.”

”How sad and disconnected I felt with the heterosexual medical staff that I was working with at the onset. I left the most prominent cancer hospitals in the New York City area because of that!!!! I have since found a Dr./team that are EXCELLENT and work quite well with me in all my ‘outness’.”

### Being out and respected can be very healing

”I was lucky and had a very positive experience. My partner was involved in every aspect of my care and wasn’t treated any differently, nor was she excluded from any decisions or information that was given to me.”

”I believe I am fortunate because my primary physician is a straight woman, but she quickly understood both me as a male and as a gay man with prostate cancer that had spread to my bones.”

”I am a 3 time Hodgkin’s survivor. I was not out my first time, but came out before my 2nd and 3rd time. My experience was great. I was fortunate to be in the hands of people who did nothing to discriminate against me or my partner.”



# 4

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## **Respecting LGBT patients means respecting their support teams**

Compared to other survivors, LGBT people have some striking differences in who they turn to for support during cancer treatment. For many people, the most important relationships exist outside of legal definitions. Traditional intake forms miss these bonds of responsibility and support. It is not uncommon for LGBT people to be rejected by their biological family due to their sexual orientation and/or gender identity and this tie is not necessarily healed following a cancer diagnosis. Treatment centers that do not welcome and respect an LGBT person's support team are subtly conveying discrimination.

## Respecting LGBT patients means respecting their support teams

### Support networks are an essential part of treatment

- ” “For LGBT people diagnosed with cancer, the first thing to ask is what kind of support network do you have and can I offer you information about LGBT-friendly networks.”
- ” “Allow the patient to say who they want with them and at what time. The most important thing is to recognize that the patient will need support so offer them as many options as possible including LGBT friendly options. Don't make assumptions and remember the focus is on a successful treatment not who the patient considers their family or support group.”
- ” “Don't be afraid to ask what someone's orientation is. It's relevant because the partner and familial relationship is important to the success of treatment...”

### LGBT support systems can differ from the norm

- ” “An LGBT person might not have the same type of support system that straight people do. They may be estranged from their families of origin; they may not be out at work or to their families, which means a diagnosis like cancer can be every scarier than for a straight person.”
- ” “My lover at the time and my ex bonded together to support me for over two years. My friends and community and doctors wrapped themselves around me.”
- ” “In LGBT people, families of choice are often more significant than families of blood relations.”
- ” “For most cancers: support during treatment may more frequently come from friends, not family.”

## Recommendations

- ✓ **Conduct a scan to see how the office/institution conveys welcome for alternative support teams**
- ✓ **Use findings to augment the message to staff and patients alike**
  - Prominently display policies ensuring alternative families are respected during care
  - Train staff in the steps to comply with the early designation of healthcare proxy
  - Include designation of healthcare proxy materials in routine intake forms
  - Allow patient to designate important support team members as well as healthcare proxy on forms and/or patient records

## Respecting LGBT patients means respecting their support teams

### LGBT people can't always count on their biological families

- “My family refused to come and told me they hoped I would die from cancer.”
- “It is important to know where it is safe to bring a partner, because my family hates me and even my mother told me right before the surgery that she hoped I would die in surgery and that she wished I had never been born.”

### Respondents needed their partners to be respected as legal spouses and offered caregiver support

- “Treat a same-sex partnership/marriage the same as an opposite-sex partnership/marriage. If the patient refers to their significant other as their ‘wife’; use that term. If they say ‘girlfriend’ or ‘partner’, use that term. Allow partners/spouses the same rights and roles as you would any other heterosexual relationship...it made a huge impression and was so very helpful that my partner was treated like any other spouse.”
- “Since my biological family refuses to have any contact with me it is essential to my health and survival that they understand that my partner IS MY FAMILY and when they treat him as such my outcomes are much better.”
- “She (my partner) was generally welcomed but treated a ‘friend’ not a ‘spouse’ and care-taker. She was never really offered emotional support by the treatment team as I noted other (straight) patient’s partners and care-givers were. She was never offered access to care-giver’s supports or resources.”

### Respecting the “chosen family” is supportive and critical to healing

- “I can’t tell you how much it helped me to know that my wife was able to interact with any Dr. or nurse associated with my care without fear of discrimination.”

## Respecting LGBT patients means respecting their support teams

- “I would not have made it through treatment without all of my friends and loved ones. They are the reason I am still here.”
- “It was very comforting and supportive for me to have my relationship with my partner be so accepted by my healthcare team. It took some of the worry out of the equation. It meant I knew I could trust the medical team to support me and my family through cancer.”
- “I was fortunate enough to have been referred to healthcare workers who acknowledged my relationship and included my partner in all aspects of treatment. Had this not been the case it would have made a stressful situation that much worse and would have had a negative impact on my experience and overall health.”
- “My partner IS MY FAMILY and when they treat him as such my outcomes are much better. He is my advocate and can remember everything I can't. Good outcomes depend on his involvement as does my emotional well being.”

### Disrespecting LGBT support systems causes extreme strain

- “My support system, many of whom are trans and gender variant people, were made to feel very uncomfortable by my doctors and medical staff due to disregard for pronoun use, sideways glances, and overall awkward responses. My friends comprised my entire support system and were critical to my care. The reluctance to respectfully interact and, in some cases, communicate clearly with my friends was extraordinarily difficult for me and lead to much added stress. I already felt so alone without my family.”
- “The hospital where I had surgery refused to let my partner see me in recovery, as she was not ‘family.’”

# 5

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## **The pervasive expectation of gender conformity can be alienating**

Cancer care is not neutral; it is rife with unexamined messages about appropriate gender expressions and concerns. For LGBT survivors, many of whom are gender nonconforming, the educational materials, pink ribbons, and expectations of breast reconstructive surgeries are particularly alienating. When LGBT people fall outside these expectations they can be isolated, stressed, or even experience substandard care.

## The pervasive expectation of gender conformity can be alienating

### Gender expectations are everywhere

”I think there is much to be studied in how orthodox gender codes affect how patients discuss (or not) their cancer journey. I noticed men who adopted traditional masculine roles of stoicism and emotional guardedness, missed out significantly on some of the vital tips and lessons that you pick up along about managing treatments and challenges. Most of all, communication styles (gendered in whatever way) govern how one socially navigates new identity issues around cancer, disease and dying/surviving.”

### Transgender survivors' needs are often overlooked/disregarded

”Don't forget to give us our hormones. Expect the unexpected. ie, don't get upset when you go to put in a Foley and find the person is pre-op. Treat us with dignity. USE THE CORRECT PRONOUNS!!!!!!”

”Providers didn't seem to know gender variance is not a sexual orientation.”

”I would tell them about my oncologist, who still, after almost 2 years of seeing him every three months, continues to refuse to understand what being transgender means. I have an incredibly difficult and uncomfortable relationship with this doctor and no way to get out of it. The lack of respect for me is unbelievable.”

”I haven't been through a legal name change, so all of my insurance info and my charts are in my old name. Some of the doctors and nurses were able to remember my chosen name, but others weren't.”

### Many lesbians are alienated by the “pinking” of breast cancer

”Reproductive cancers are loaded with gender issues. For example, not all women (or men) with breast cancer want to wear pink. I think over-feminizing BC is problematic.”

”I hate the pinkness/cuteness of all things surrounding breast cancer...I hate the push by many to get reconstruction surgery.”

## Recommendations

- ✓ **Conduct a scan to see when the office/institution presumes gender conformance in care**
- ✓ **Use findings to build welcome for all gender nonconforming patients**
- ✓ **Due to the high chance of poor care, get input on the treatment of transgender patients and make changes to augment their welcome**
  - Review educational materials for gender presumptions
  - Offer LGBT-specific educational materials which particularly avoid gender conformity expectations
  - Include training on gender assumptions in mandatory cultural competency care
  - Convene focus group of former transgender patients to get input on satisfaction and enhancements
  - Add transgender community leaders to community advisory body for ongoing level of input

## The pervasive expectation of gender conformity can be alienating

### Gender-conforming and heterosexist assumptions are too often made about body image changes following cancer treatment

- “Being a Lesbian facing having your breasts cut off, it would be good if they did not assume you were concerned about how ‘men’ would see you in the future!”
- “I really resented assumptions about my priorities. There’s a hell of a lot of emphasis in the breast cancer awareness movement and in group oncology practices about helping women look stereotypically feminine. I personally have no interest in breast reconstruction, and it irked me that I was automatically referred to a plastic surgeon at the time of my mastectomy. It irked me that reconstruction was so pushed in the patient ed materials...”
- “Well, I had one positive thing happen to me because of my breast cancer experience. To wit, I was given a total, bilateral mastectomy with male chest reconstruction as a part of my treatment. This was definitely a silver lining and if you can avail your patient of something positive that can come from their situation, be sure to make every effort to do so. It meant the world to me.”

## 6

## LGBT survivors need more culturally appropriate support and information

Patient-centered LGBT cancer care requires that healthcare providers be knowledgeable about cancer's unique impact on LGBT relationships, families, sexuality, and fertility. Unfortunately, this is rarely the case, leaving LGBT survivors to struggle to get culturally appropriate information. Because so many of LGBT survivors' concerns are not met in traditional cancer care settings and support groups, they expressed a strong desire for separate groups where they could discuss their lives openly. Sadly, in the absence of clear information, some survivors wondered whether their sexual orientation caused their cancer. The lack of locally or nationally accessible information and support resources for LGBT people with cancer is another way the health care system conveys a lack of welcome.



## LGBT survivors need more culturally appropriate support and information

### LGBT survivors need culturally-sensitive mental health referrals

- ” “My experience was very isolating. My healthcare providers were cognizant of that and it was a tremendous benefit. I think referrals to mental health and support persons would be good any time this happens.”
- ” “Social workers should know about LGBT resources, including counselors.”

### LGBT patients want to talk about sex

- ” “I think we might be able to discuss more openly how sex and sensuality can be an important part of coping/healing/recovery processes. I thought this aspect was underplayed and even stigmatized in most environments, but to me it was one of the reasons I fought to survive.”
- ” “Luckily my radiologist could talk about how the treatment might affect my sex life and used terms and concepts that indicated an understanding of gay men’s sexual behavior (for example he asked who was the top and who was the bottom etc).”
- ” “I am a gay male and a bottom. The chemo, hormone, surgery and radiation took almost two years—during which I lost all sex drive and my penis shrank. Erectile drugs have created a different erection than I used to have. I would have appreciated more detailed, comprehensive information about what to expect.”

### LGBT patients need accurate information about fertility planning

- ” “Treat family and family planning issues with the same concern as for straight patients.”
- ” “Please offer us fertility options.”

## Recommendations

- ✓ **Collect referral lists for LGBT-welcoming providers, including local mental health providers**
  - Call referral sources in advance to ask if they are LGBT welcoming and follow up with the patient to ensure they were welcomed
  - Offer referrals to LGBT support groups or develop one if none exist
- ✓ **Review all educational materials to remove heterosexist language choices: i.e. “husband” “married,” etc.**
- ✓ **Ensure providers are educated in how to speak about sex and sexuality to LGBT patients**

## LGBT survivors need more culturally appropriate support and information

### Many people wanted LGBT support groups

- “I would like to stress that not all LGBT have a support system. Some are isolated from many social situations and are lonely, have no one to turn to, and are in need of caring and love from somewhere. Some are not active in the gay community for one reason or another.”
- “Since gender variant people are not allowed in groups which pertain to reproductive system cancers, alternative support should be offered.”
- “Having a gay male support group was the best thing that happened to me. I feel very lucky to be able to discuss both feelings and sensations without any inhibition at all in the company of other gay men who also had prostate cancer.”
- “I would love to get hooked up with other FTMs that have had breast cancer, and be given access to any resources available to us.”
- “Caregiver groups are important too!”

### Lack of information led some respondents to wonder if their cancer was caused by being LGBT

- “I had moments when I questioned whether my lifestyle (being a lesbian) contributed to cancer.”
- “The diagnosis was extremely depressing and caused a lot of mental anxiety about my sexuality and my life in general. As a young gay man who had recently become sexually active it was upsetting to get cancer as a result of being gay. I think this led to additional mental isolation that took a few years to overcome.”
- “As a gay man we tend to want to look PERFECT, great bodies and great tan. I used tanning booths and they increase your chances of getting Malignant Melanoma by 75%. This [is] how I got it.”

# Summary of Recommendations

## Stigma Plays a Prominent Role in LGBT Healthcare

### RECOMMENDATIONS:

**Providers and healthcare management should take additional steps to become educated about the stigma-related stress many LGBT people carry into treatment & strategies to reduce such stress**

- Provide cultural competency training
- Include LGBT leaders on community advisory bodies

## The Local Healthcare Environment Determines One's Experience and is Highly Variable

### RECOMMENDATIONS:

**Healthcare institutions and offices should actively convey that LGBT-welcoming behavior is a core expectation of all staff**

- Include mandatory staff training
- Reinforce such welcome through the actions of management and public relations staff. For example, an article could be written on LGBT diversity for an employee newsletter

**Healthcare institutions and offices should convey a zero-tolerance environment for any discriminatory behavior on the part of staff**

- Include scenarios and possible responses in annual staff trainings

**Healthcare institutions and offices need to broadcast their LGBT-welcoming policies and training to potential and current patients**

- Include LGBT measures and nondiscrimination protections on intake forms
- Prominently displaying LGBT protections/welcome on website and in waiting rooms
- Partner with local LGBT community based organizations for public events, in public materials
- Tailor ads to LGBT media outlets
- Participate in and display the results from the Human Rights Campaign Healthcare Equality Index report card

**It is particularly important for LGBT-welcoming policies and training to be broadcast to the public in situations where there's greater historic stigma, such as in religious institutions, or regions with no LGBT civil rights protections**

**Cultivate the safety of LGBT employees to be out at the workplace**

- Sponsor an LGBT employee group
- Include LGBT status on employee satisfaction survey; ask about safety and being out at work

## Disclosure is Often Related to Perceived Safety

### RECOMMENDATIONS:

**Collect evidence to see if LGBT patients feel safe coming out at your institution, use evidence to build safety**

- Ask about LGBT status on patient satisfaction surveys
- Ask about LGBT status on employee surveys and their relative safety
- Convene LGBT employees as an advisory body, to suggest steps to increase patient safety
- Include LGBT leaders on community advisory bodies to provide a constant source of feedback
- Conduct an environmental scan of the facility to check how and when safety is conveyed to LGBT patients

# Summary of Recommendations

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## Respecting LGBT patients means respecting their support teams

### RECOMMENDATIONS:

**Conduct a scan to see how the office/institution conveys welcome for alternative support teams**

**Use findings to augment the message to staff and patients alike**

- Prominently display policies ensuring alternative families are respected during care
- Train staff in the steps to comply with the early designation of healthcare proxy
- Include designation of healthcare proxy materials in routine intake forms
- Allow patient to designate important support team members as well as healthcare proxy on forms and/or patient records

## The pervasive expectation of gender conformity can be alienating

### RECOMMENDATIONS:

**Conduct a scan to see when the office/institution presumes gender conformance in care**

**Use findings to build welcome for all gender nonconforming patients**

**Due to the high chance of poor care, get input on the treatment of transgender patients and make changes to augment their welcome**

- Review educational materials for gender presumptions
- Offer LGBT-specific educational materials which particularly avoid gender conformity expectations
- Include training on gender assumptions in mandatory cultural competency care
- Convene focus group of former transgender patients to get input on satisfaction and enhancements
- Add transgender community leaders to community advisory body for ongoing level of input

## LGBT survivors need more culturally appropriate support and information

### RECOMMENDATIONS:

**Collect referral lists for LGBT-welcoming providers, including local mental health providers**

- Call referral sources in advance to ask if they are LGBT welcoming and follow up with the patient to ensure they were welcomed
- Offer referrals to LGBT support groups

**Review all educational materials to remove heterosexist language choices: i.e. "husband" "married", etc.**

**Ensure providers are educated in how to speak about sex and sexuality to LGBT patients**

# Conclusion

Cancer doesn't discriminate, but the healthcare system often does, as evidenced by the many experiences reported here by survey respondents. These experiences, while taking place at one of the margins of the healthcare system, offer a rare glimpse into the opportunities for change in the entire system. A well-intentioned one-size-fits-all approach too often gives a message of unwelcome to LGBT patients, leading those who can avoid the system to do so, and suggesting to others that they need to remain silent about their lives, their support systems and their needs.

Discrimination and its cousin, secrecy, lead unquestionably to poorer health outcomes. This information, at the heart of patient-centered care, is fairly new for researchers, policy makers, and healthcare administrators, but the message needs to better reach LGBT patients and survivors as well. Many don't appear to know that equitable treatment is not a luxury; their experience with the medical system is an essential measure of their health. For example, one survey respondent reported that her cancer care was "not at all" affected by her LGBT status, but later noted that half of her providers were particularly "thoughtless and inappropriate" on LGBT issues. Her dissatisfaction was so extreme that she "ended up changing doctors to get the same treatment but less stupidity." This apparent contradiction may lie in her misperception of "quality of care," imagining that it is only measured by medical decisions, blood work and scans. This example also illustrates how easy it is to miss capturing data on patient dissatisfaction. To avoid false positives, measures of satisfaction, or quality of care should explicitly ask patients about *satisfaction with provider treatment* in addition to perceptions of *medical decision making*.

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**For many LGBT people, their lives may depend on whether the changes recommended in this documents ever take place.**



[cancer-network.org/patient\\_centered\\_outcomes](https://cancer-network.org/patient_centered_outcomes)