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LGBTQ PEOPLE AFFECTED BY CANCER REPORT

APRIL 2018

BRIGHTON AND HOVE LGBT SWITCHBOARD

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LGBTQ PEOPLE AFFECTED BY CANCER REPORT

MARCH 2018

[Macmillan Cancer Support](#) has commissioned Brighton and Hove [LGBT Switchboard](#) to conduct a series of consultation and engagement activities with Brighton & Hove and Sussex-based lesbian, gay, bisexual, trans and queer (LGBTQ) people affected by cancer, and those supporting them. This engagement work will be used to inform how LGBTQ people affected by cancer can be best supported; and to identify areas where improvements to patient experience can be made through Macmillan and in collaboration.

Please note, the following report presents information about the consultation and engagement work conducted by LGBT Switchboard, and should not be taken as a position statement of Brighton and Hove LGBT Switchboard or of any participating organisation.

1. INTRODUCTION

This report presents data from two online surveys: one of LGBTQ people in Brighton and Hove and Sussex about their experiences with cancer diagnosis, treatment and support, and a second survey for professionals and volunteers working with them. The report also presents feedback gathered through two focus groups, one for local LGBTQ people affected by cancer, and one for professionals and volunteers working with them. A total of 6 interviews were also carried out; two with LGBTQ people affected by cancer and four with professionals involved in supporting LGBTQ people affected by cancer.

1.1 BACKGROUND

Macmillan's '[Emerging Picture: LGBT People with Cancer](#)¹' document notes that 'at present there are limited robust data on the numbers of LGBT people living in the UK, and therefore there is also a lack of robust information on the number of LGBT people living with cancer in the UK.'

In their report '[No One Overlooked: Experiences of LGBT people affected by cancer](#)²' Macmillan highlights the fact that 'successive Cancer Patient Experience Survey (CPES) reports have shown that LGB cancer patients have poorer experiences of cancer services than their heterosexual counterparts. For instance, the recent 2013 CPES revealed that LGB patients have showed statistically significant differences to their heterosexual counterparts in respect of 24 dimensions of experiences. These include communication, the management of pain, and access to adequate practical and emotional support (from healthcare professionals in primary and secondary care, but also from self-help groups for people with cancer).' The CPES does not monitor participants' trans status, so there is a real lack of research data about trans patients' experiences with cancer.

Macmillan recognises that people affected by and living with cancer from different communities, have varying needs and experiences of accessing cancer services. With this, the impact of a cancer diagnoses is not only experienced by the patient, but also carers, friends and family.

There is a commitment from Macmillan to explore and understand the needs and experiences of people from all communities and backgrounds, including those who identify as Lesbian, Gay, Bisexual or Transgender through listening to patients, carers and family members in a meaningful and genuine way.

The indication that LGBT people living with cancer report a poorer experience of cancer services in comparison to other patient groups highlights a need to look at why and how these experiences are as such - and importantly identify areas of improvement that can be made. No assumptions have been made about what these changes could be or realised. Macmillan Cancer Support has a clear role in supporting health and social care service providers in recognising these needs, influencing and supporting change and working in partnership to improve the experience of LGBT people living with cancer, their carers, family and friends.

This evidence and insight has led to a partnership between Macmillan Cancer Support and Brighton and Hove LGBT Switchboard to engage people affected by and living with cancer from the LGBTQ community in and around Brighton and Hove. This geographic area in particular has been identified as there is a proportionately large LGBT community living, working and accessing services in the area.

Everyone diagnosed with cancer should have access to the appropriate help and support they need and treated as a person with a life and not simply a disease and this work will help to ensure that all LGBT people living with cancer receive this with a positive experience. The insight and feedback offered by those participating in this work has been used to form recommendations of what improvements could be made to improve the experience of people with cancer within the LGBT communities.

1.2 AIM

The aim of this research exercise was to gather experiences of cancer from both LGBTQ people and professionals in Brighton & Hove and Sussex, to identify any barriers which prevent LGBTQ people from accessing equal information, care and support in their cancer pathways.

This is to ensure that LGBTQ people's voices are heard and that their needs can be taken into account in any developments to improve access to cancer information, care and support.

2. METHOD

2.1 ONLINE SURVEYS

Two online surveys were carried out. One was aimed at professionals and volunteers supporting people affected by cancer (35 respondents), and the other was for LGBTQ people affected by cancer (26 respondents), including partners/family members/friends of LGBTQ people affected by cancer.

All survey questions were developed and agreed by Macmillan Cancer support and Brighton & Hove LGBT Switchboard. Some questions for the community members' survey were developed in line with questions taken from the [NHS' National Cancer Patient Experience Surveys](#). The surveys were conducted using SurveyMonkey over a period of ten weeks in January - March 2018. Paper copies of

the survey were also advertised alongside links to the SurveyMonkey online form and offered to local community organisations for distribution to their clients, but none were requested.

The surveys were promoted and distributed through a variety of channels including Switchboard's LGBT HIP [Health Improvement Project] members' list, Switchboard's social media channels on Facebook and Twitter, email lists for Community Works, Community Base and all LGBT Switchboard staff and volunteers. Macmillan promoted the engagement work through channels including social media, Sussex-based cancer services, The Horizon Centre and local cancer support groups. A press release was sent to local media and resulted in a radio interview on BBC Sussex.

Survey responses have been analysed and reviewed by Switchboard's LGBTQ Development Officer, Chris Brown, and qualitative responses have been reviewed to identify key themes and extend quantitative findings.

2.2 INTERVIEWS AND FOCUS GROUPS

Unfortunately, on both surveys, but particularly the survey for LGBTQ people affected by cancer, a number of respondents skipped several questions, resulting in a smaller data set than hoped for. As a result of this, we introduced six interviews into the engagement work.

Interviews were carried out with two local LGBTQ individuals affected by cancer, and with four professionals and volunteers involved in supporting people affected by cancer. Two focus groups were also held, one with three local LGBTQ people affected by cancer and one with two professionals and volunteers supporting people affected by cancer. All interviewees and focus group members have given permission for their conversations to be included in this report. All professionals have given permission for their names to be used.

3. DEMOGRAPHICS

All demographic information about survey respondents is included in the appendices at the back of this report.

4. FINDINGS: INTERVIEWS

The write-ups of interviews carried out with LGBTQ people affected by cancer, and with professionals and volunteers supporting people affected by cancer, are outlined below. All interviews were carried out by Chris Brown, LGBTQ Development Officer, Brighton & Hove LGBT Switchboard.

4.1 INTERVIEW ONE: LGBTQ PERSON AFFECTED BY CANCER

Person A is a 53-year old lesbian who is now cancer free following treatment for hormone positive G2 breast cancer. She was diagnosed at the Park Centre for Breast Care, Brighton, after a routine mammogram when she turned 50. Her treatment included a lumpectomy at The Princess Royal Hospital in Haywards Heath, and radiotherapy at the Sussex Cancer Centre in Brighton. The interviewee's partner was present at almost all meetings that she had with her healthcare professionals.

When asked about any barriers that she experienced throughout her treatment in relation to her sexual orientation, Person A said that she has always been 'out' about her sexual orientation with all her healthcare providers. She said that while accessing treatment in Brighton she experienced no barriers, and that staff were all very inclusive. However, at The Princess Royal, when she attended her pre-op meeting, she was asked who her next of kin was. When she gave her female partner's name this was queried, which the interviewee said made her 'very cross' as she did not believe this would have happened if she gave a male partner's name. At The Sussex Cancer Centre, she said that the surgeons always treated her partner as next of kin.

The interviewee also described her experience on the day of her surgery at The Princess Royal. She was asked repeatedly if there was any possibility she might be pregnant. She refused to take a pregnancy test, saying that she was a lesbian and had not had sex with a man for 25 years. She felt repeatedly pressured to take the test and was asked by a further two or three staff members if she might be pregnant. She said they were less insistent when she returned for a second operation.

Unfortunately, when Person A returned home post-surgery, she developed a bad infection two weeks later, and was treated by a GP who prescribed the wrong antibiotic, which led to her needing to be seen at A & E. From there, she was sent to the Park Centre where her treatment was taken over by a nurse who prescribed a more effective antibiotic. She then returned home for several days where her partner needed to change the dressings daily on this serious infection. This was quite problematic and upsetting for them both, and the interviewee asserted herself in asking the Park Centre to change the dressing daily, which was done. She wondered how she would have fared without being able to be so assertive, or without having such a supportive network.

The interviewee was given a Breast Cancer Care resource pack from the Breast Cancer Care charity and noted that while there were images of older and BME women, there were no images of identifiable lesbian or bisexual women, and that the resources were all very heterocentric. She said her partner felt left out when looking through the literature. The interviewee wrote to the charity about the lack of representation in the resources but never received any reply.

The interviewee said that she felt that patients' outcomes and experiences would generally be better if patients were able to be assertive and if they had a supportive network. She felt that some LGBTQ people might face more challenges if they don't have the support of their families as can be the case for some.

Asked about what could improve experiences for LGBTQ people being treated for cancer, Person A remarked on the need for a 'total baseline' of awareness with cancer professionals of lesbian, gay and bisexual people's needs and of the importance of recognising their relationships. She felt that awareness of trans issues was also important but that awareness needs to be raised separately from lesbian, gay and bisexual issues. She noted that a Charter of Rights for LGBTQ people and a right to complain about inequalities would also be useful.

The interviewee spoke about the importance of including representation of LGBTQ people in cancer resource material including posters, leaflets and websites. She felt that monitoring patients' sexual orientation, gender identity and trans status would encourage LGBTQ people to be more open. She said that if she had not had her partner with her at appointments, as she 'looked straight,' she would need



to out herself if she wanted her needs to be met as a lesbian woman. She felt it would be easier if she was asked about her gender identity and sexual orientation.

4.2 INTERVIEW TWO: LGBTQ PERSON AFFECTED BY CANCER

Person B is a gay man aged 64 who volunteers with a local charity raising awareness of the early signs of cancer and the benefits of seeking advice from a GP, as soon as possible. The interviewee has occasionally provided support to LGBTQ people affected by cancer within his own circle, using the information he has learned during his volunteer experiences.

This person had his bowel cancer diagnosed early on when he recognised some possible symptoms (he says his previous volunteer role equipped him to be alert to signs) and went to his GP. The GP sent him to the Royal Sussex County Hospital (RSCH) for assessment. He was allocated a Macmillan Clinical Nurse Specialist. His cancer was treatable through surgery and he didn't require any radiotherapy or chemotherapy. He is now in remission. He rated his NHS care as 10/10.

This person described taking a gay male friend to RSCH to find out if he had a cancer diagnosis; he was single at the time. He was seen by a senior Macmillan nurse who didn't use the word 'cancer' once, even when asked directly if the diagnosis was cancer; instead the nurse used words like 'growth' and 'blockage.' He found this very frustrating and annoying. Post-diagnosis he was not offered any information about local cancer support groups but felt that he didn't need them anyway, as his close friend was, in effect, his support group, as were other friends and his family.

He commented that support would be much harder to access for LGBT people who might be single and not have the awareness of cancer that he already had through his voluntary work. He gave the example of a friend of a friend: a gay male who had lumps in his chest and was the only man attending breast cancer screening – an experience that he found very intimidating. He also gave the example of transgender people attending screenings with people of the opposite gender and finding this distressing.

The interviewee has occasionally provided support to LGBTQ people affected by cancer in his voluntary role. However, he feels that it is not important that cancer professionals are aware of patients' sexual orientation as "they would disclose if they thought it was important." When he was in hospital a decade ago, with the support of his then partner, he didn't feel that his sexual orientation was an issue in any way. His GP is aware that he is gay and in a relationship and this has caused no problems in any way.

When asked about potential barriers to accessing information, treatment and support, the interviewee felt that assumptions are made that all patients are heterosexual. He described his experience of, as an inpatient, having a female nurse 'coming on strong' to him and having very inappropriate conversations with him about food and sensuality. The next day when his gay male friend visited him they marched around together singing the Wedding March to give the nurse a clue about his sexual orientation.

He also described the experience of his lesbian niece, who was told that she didn't need cervical screening as she was not having sex with a man.

The interviewee went on to say that he was aware that many female sex workers are lesbian but in terms of cervical screening many would be put off going as they would feel uncomfortable disclosing their sex work.

He commented that a colleague of his at the charity he volunteers for described that many women are afraid of cervical screening, perhaps because of past negative experiences, and that their project is

helping to get the word out about the importance of going for screening. He said that Brighton & Hove has one of the lowest rates on take-up for cervical screening in the UK.

The interviewee also felt that transgender people do not receive adequate information about the need for cervical and prostate screening, but that he gets the word out to his friends and community members.

He noted that his charity team leader is trained in LGBTQ-inclusive language and terms, and that he and his colleagues want to 'get it right.' He felt that some gay men might be uncomfortable discussing their sexual health because assumptions might be made about them, e.g. that all gay men enjoy anal sex. He commented that if cancer healthcare professionals know a man is gay, and sexually active, they can give specific information about, for example, the possibility of erectile dysfunction and ways to manage it. In his opinion older gay men find it harder to come out to their GP or healthcare professional without a specific reason, so might go to 'the clap clinic' instead with possible cancer symptoms.

4.3 INTERVIEW THREE: PROFESSIONAL INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Martin Hogan works at The Horizon Centre as a Macmillan Acute Oncology/Cancer of Unknown Primary Nurse Specialist. In his role he works closely with GPs around the Brighton and Hove area and is also a group member of the Trust LGTB forum and Values and Behaviours Champion within the Oncology directorate.

Q1: How frequently do you come into contact with LGBTQ patients?

Martin usually sees 5 or 6 LGBTQ patients each week, generally in Accident and Emergency or on the acute floor. Sexual orientation, gender identity and trans status are not monitored in A & E so Martin learns about their LGBTQ identities when he carries out a holistic assessment, asking questions like "Tell me about you..." or "Who lives at home with you?" He believes that because he is visibly identifiable as a gay man himself, LGBTQ patients may be more likely to come out to him.

He's not sure how many transgender people he supports; unless they disclose their trans status during his holistic assessment. Martin says that research shows trans people are less likely to access treatment due to the fear of negative outcomes if they disclose their trans status.

At this stage many of them are unaware they have cancer so he is involved in breaking the news to them and referring them for support and signposting.

Martin believes that routinely monitoring patients' sexual orientation, gender identity and trans status could really improve patient experience throughout services and systems and could help LGBTQ patients feel more 'cared for' by the Trust.

Q2: Do you consider an understanding of someone's LGBTQ identity important in delivering best cancer care?

Martin said yes, especially in terms of the research regarding health inequalities for LGBTQ people. Martin gave the example of the need for trans women to be monitored and assessed for prostate cancer but one trans woman being invited to attend a men's clinic and walking into a waiting room full of men. He remarked on the need for health promotion education for the LGBTQ community, including specialist promotional materials and clinics.

Q3: In your experience what barriers do LGBTQ people experience in accessing diagnosis, treatment, support and care?

Martin feels the main barriers are in accessing relevant education and health promotion information. He gave the examples of lesbians being (erroneously) told by their GPs that they don't need screening for cervical cancer. Martin had attended a study day some time ago called 'Bringing Cancer Out of the Closet' and became very aware of the lack of representation of LGBTQ people in Macmillan's promotional materials.

Again, Martin referred to the issue of trans women needing to be monitored for prostate cancer but lacking adequate information about this issue. He also made a connection to the issue of a higher rate of smoking with gay men in particular, and the need for specific health promotion materials for this group about the risk of lung cancer.

As well as the need for health services and Macmillan to develop LGBTQ specific health promotion materials, Martin felt there was a need to take those materials into LGBTQ spaces such as pubs and other community environments.

Martin also commented on the need for LGBTQ awareness training for cancer professionals working in hospitals and community settings. He felt that it was possible that LGBTQ patients might not always be treated kindly and compassionately. He gave the example of a gay man presenting at A&E with rectal bleeding, which can be a symptom of cancer, but might be read as the result instead of anal sex, which could lead to less compassionate treatment.

Martin felt that HIV-related services respond very well to LGBTQ people as they have had specialist training. This is particularly important due to the increase in HIV-related cancers, as Martin noted.

Martin said that while palliative care is very inclusive, with a diverse and very well-trained workforce, the greatest barriers for LGBTQ are primarily diagnostic. He noted that many LGBTQ patients may not disclose potential cancer signs to their GPs because of their fear of discrimination, and that if they don't have a good relationship with their GP they may not feel welcomed or heard.

As an example of poor communication Martin told the story of a 45-year-old lesbian being told by her GP that she had an ovarian cyst, and the GP wanting to 'bring her husband in' to disclose the bad news. When she told the GP that she had a female partner he said that she did not need anyone there after all and told her there and then that she needed to have a hysterectomy.

He felt that these issues reflect both wider societal issues of homo-/bi-/transphobia and a lack of training for GPs and other healthcare staff. With healthcare staff a lack of experience working with LGBTQ people could also be a factor, and the lack of monitoring makes it difficult for staff to be aware of individual LGBTQ people's needs. Another barrier for staff to working with more specific needs, e.g. those of trans women with prostate cancer, is their heavy caseloads.

Q4: How can cancer services and support excel at being LGBTQ inclusive?

The main issues here for Martin were related to better health promotion and education. He thought that bringing cancer-related education opportunities into LGBTQ community settings would be helpful, e.g. having a drop-in at community bars and pubs, and a float/stall at Brighton Pride.

He also felt that all healthcare professionals, including district nurses and hospital staff, should receive training about LGBTQ inclusive practice and trans awareness.

Martin would like to see an LGBTQ champion in each department or community setting, who could champion LGBTQ rights and deal with any specific areas within their remit, for example encouraging complaints at A & E to identify and respond to issues, and feed learning back to staff after action reviews.

Martin would like to see Macmillan's materials become LGBTQ inclusive, with representation of lesbian, gay, bisexual and trans people. He felt it was important for there to be specific resources for each group, rather than 'one size fits all' LGBTQ resources. LGBTQ-inclusive posters and leaflets would work well in GP waiting rooms and improve access to cancer information for LGBTQ patients. Martin also suggested a Brighton and Hove-specific website that could be promoted by local healthcare providers and in local newspapers and magazines.

In closing, Martin noted that Macmillan nurse specialists and consultants are all very willing and eager to improve their LGBTQ-inclusive practice.

4.4 INTERVIEW FOUR: PROFESSIONAL INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Katie is a counsellor at the Patient and Family Support Team, [St Catherine's Hospice](#), Crawley. Katie estimates that she supports perhaps three LGBTQ people affected by cancer each year. She visits people in their own home to provide counselling. Katie only knows about clients' sexual orientation, gender identity or trans status if they self-disclose – she doesn't think the Hospice's Cross Care system monitors these aspects of people's identities.

St Catherine's Hospice supports people as inpatients receiving end-of-life care, and also people receiving palliative care. Katie says that anyone can apply for counselling and there are no barriers for LGBTQ people in terms of applying for the service. She says the admin team is very inclusive and that staff across the board use gender neutral terms. There are LGBTQ people represented on the board and at management level which contributes to the inclusiveness of the services. All staff take mandatory NHS e-learning which includes a section addressing inclusion. The counselling service provides opt-in LGBTQ awareness training to all its volunteers.

Katie thought that perhaps St Catherine's website shows images of mainly white people and is heteronormative, and that more LGBTQ representation on the website and other materials would be positive but also have a cost implication.

In terms of ways to improve LGBTQ inclusion, Katie thought that all staff should receive an LGBTQ awareness training workshop, which should include specific content on understanding and responding to the needs of transgender patients. She noted that an LGBTQ affirmative statement would be valuable. Katie also commented that Muslim people are less likely to use the hospice facilities and that it would be helpful to understand why this is and learn whether there are other barriers affecting LGBTQ Muslims.

4.5 INTERVIEW FIVE: PROFESSIONAL INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Jude Murray is a yoga therapist specialising in cancer, holding some classes and also carrying out some 1:1 sessions.

How frequently do you come into contact with LGBTQ people affected by cancer?

Jude estimates, based on self-disclosure, that roughly 25% of her clients identify as LGBTQ. She notes that people are much more likely to disclose aspects of their identities if they have a relationship with their practitioners that is based on trust.

In general, how confident do you feel in providing support to LGBTQ patients and their carers?

Jude feels very confident, but not 100%. She is very aware of the needs of LGBTQ people based on her own lived experience and listening to the stories of LGBTQ people. Jude would be interested in accessing further training into the needs of LGBTQ people affected by cancer but is not sure what training would be most helpful; as she said, “You don’t know what you don’t know.” Any increase in understanding would be positive for her work; at present she responds to needs based on her ‘empathic guesses.’

From her own lived experience, she understands that queer people may have become used to humiliation and may feel that they can’t ‘make a fuss,’ perhaps coming to accept that their own needs might not be met.

Do you consider an understanding of someone’s LGBTQ identity important in delivering best cancer care?

Jude responded with an emphatic yes, and gave many reasons, including the need for trans people to be addressed and referred to with the correct pronouns and gender orientations. As a yoga practitioner she has removed all gender-specific terms from her vocabulary, e.g. using ‘chest’ rather than ‘breast,’ and she doesn’t assume that people all have the same anatomy. Jude comments that this is particularly important when practitioners are working with the body therapeutically and with its psychosocial impact.

Jude talked about the effects of cancer and its treatment for some people on hair loss, sexual function and relationships, and how important it is to understand people’s gender experiences in order to offer appropriate and relevant support, for example meeting the specific needs of trans women with prostate or testicular cancer, who should have their dignity and modesty preserved.

In your experience what barriers do LGBTQ people experience in accessing diagnosis, treatment, support and care?

Jude noted that she spoke not as an expert but from her experiences and perceptions of supporting LGBTQ people affected by cancer. She commented on having met people with cancer of the genitals who had received deeply invasive treatments, including a trans man with vaginal cancer. For him, the focus on his vagina was deeply distressing to him, and she noted that treating him may also have been uncomfortable for his healthcare professionals.

Jude felt that some trans people might be put off accessing cancer screening for the opposite gender, particularly as most screening information doesn’t focus on the needs of trans people. She commented on the barriers experienced by lesbians, gay men and bisexual people in the general context of heteronormative assumptions being made by healthcare professionals. Jude gave the example of lesbians who were not out being asked “Is your husband coming in?” rather than ‘partner,’ and of lesbians being written to as ‘Mrs.’ She felt that language and assumptions are a large part of creating barriers for LGBTQ people.

Jude had witnessed gay men in a cancer treatment setting being seen as ‘fun,’ and objects of humour who were gently ridiculed in relation to their sexual orientation. She’s seen assumptions being made about sexual behaviours once a person’s LGBTQ identity is disclosed.

She has also encountered people who have been estranged from their families because of their gender identity or sexual orientation, noting that there might be an assumption that LGBTQ people have supportive family networks when they don't.

Jude also spoke about the experience of a lesbian she knew of who had become estranged in earlier life from her parents because of her sexual orientation. When she became ill with breast cancer and knew she was dying, she really wanted to reconnect with her family but felt the barriers were too great.

How can cancer services and support excel at being LGBTQ inclusive?

In Jude's opinion, all cancer service providers need to be fully LGBTQ-aware; that awareness needs to be informed directly by LGBTQ people with lived experiences with cancer. In her experience, training often focuses on legal issues rather than human experiences.

Jude commented that this awareness needs to go beyond 'political correctness;' that *"all humans have the right to have the whole of their experience considered during cancer treatment, not just the part that's wrong with them."* A shift in thinking should not be seen as an imposition on service providers but as a normalising of respectful, gender neutral language.

She also noted the need to raise awareness of cancer signs, symptoms and screening in LGBTQ communities – online, in GP surgeries, sexual health clinics and more. Some trans-specific resources are needed. In her opinion a lot of cancer information for women seems outdated.

4.6 INTERVIEW SIX: PROFESSIONAL INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Emma Frost is the Engagement & Volunteering Manager – South & East of England, Macmillan Cancer Support. Her role includes leading the development and delivery of a community and volunteering plan to put people affected by cancer and enabling diverse communities to influence, co-design and co-produce services and Volunteering. Her current relevant experience includes:

- National Voices – NHS Leadership - Lived Experience Facilitator for NHS Elizabeth Garrett leadership program. This is up skilling clinical and non-clinical management to understand and see the whole person. Emma says, *'As part of the role I impart my health journey/literacy and how I had to become the expert of my health, needs and preferences. A consequence of this has been educating the professionals and pathways about me as a person and my sexual identity which meant they considered me as a whole not just a set of conditions.'*
- Outreach Youth – Trustee & Chair of LGBTQ youth group for teenagers and families across the East of England. Championing rights and influencing training in schools for LGBTQ teenagers and support for their families.

Past roles:

- Person-centred planning and disability equality trainer – delivered training, advocated and facilitated person centred planning for young adults with developmental difficulties. Specifically developed and LGBTQ support group for those with developmental difficulties.
- Senior Professional Engagement manager for MS Society – UK wide remit integrating and coordinating engagement and educational resources and pathway design for Health & Social care. Developed specific e-learning and co facilitated training for professionals to understand the needs of people with MS. Developed a specific element for LGBTQ around literature visibility.

Q1: How frequently do you come into contact with LGBTQ patients?

Emma doesn't do much direct with people affected by cancer in her current role, but she sits on a Patient Participation Board with fifteen members, none of whom identify as LGBTQ as far as she is aware.

Q2: Do you consider an understanding of someone's LGBTQ identity important in delivering best cancer care?

Emma responded with a clear 'Yes'. She feels that LGBTQ people may be concerned, perhaps based on past experiences, that their identities may hinder access to services and support. Emma gave her own personal experiences as an example. She had a GP who was very good but assumed Emma (who is a lesbian) was straight. As a result of this heteronormative assumption Emma was referred into the wrong care pathway for her health condition, and she assumes others may have had similar experiences.

Emma described how different her experience was when – for the first time – she had a female gynaecologist, who 'treated her like a whole person' and didn't assume that Emma wanted to have children. Emma also described being spoken to by a junior nurse who said 'You might not want me to touch you, given that that's your preference.' Emma did want a female to carry out the examination so then felt she had to educate the nurse about her needs and preferences. She noted that lots of LGBTQ people feel they need to educate their healthcare professionals about their experiences, needs and preferences, which takes a toll on them. She said that as an expert patient, she is better resourced than many LGBTQ people to do this self-advocacy, but it is always time-consuming, tiring and uses much-needed energy when already unwell.

Q3: In your experience what barriers do LGBTQ people experience in accessing diagnosis, treatment, support and care?

Emma commented on a wide-ranging variety of barriers, in particular those affecting trans people, giving the example of trans women with a 'male cancer' (e.g. testicular or prostate cancer) who 'might feel they have to sacrifice their gender identity in order to access a treatment pathway' for their cancer. She commented on a particular situation in which a trans woman with prostate cancer felt that her gender identity was totally sabotaged by her cancer treatment, with untold negative consequences for her mental and emotional health.

Emma noted that most existing cancer literature and information is geared towards a heterosexual, cisgender audience, with very low visibility of LGBTQ couples and individuals. This semiotics has an impact for the LGBTQ community; in her role she has had feedback from a few young gay men who have felt that literature was not relevant to them as it mainly represented older, straight men.

Emma described the barriers that prevent some lesbians from going for cervical screening. She is aware of situations where lesbians have been told that they don't need cervical screening if they're not having penis-in-vagina sex. Emma also noted that some lesbians may have negative experiences of cervical screening, especially if they are not used to penis-and-vagina sex. Cervical cancer is one of the most treatable cancers if an early intervention is received, so these barriers can have profound consequences.

Emma discussed the interactions between LGBTQ people's experiences with cancer and with their mental health. In a previous role she knew a gay man with bipolar disorder and testicular cancer who

experienced his cancer diagnosis as traumatic. The diagnosis triggered his bipolar disorder but his cancer was treated without acknowledging the impact this was having on his mental health. In Emma's experience if cancer and mental health conditions are not cared for in a 'married up' way, people can experience very bad patches with their mental health.

She also commented on the levels of trauma that most LGBTQ people have already experienced in their lives in terms of coming out and experiencing homo/bi/transphobia. In her opinion, this trauma can delay or prevent LGBTQ people from accessing treatment for their mental health. Emma noted the higher rates of depression, alcohol addiction etc. in LGBTQ people but feels that these areas of people's lives, including cancer, can lead to them being 'siloes' by healthcare professionals and not seen as whole people.

Emma noted that mental health advocacy might be useful for some LGBTQ people in their meetings with cancer clinicians because if their mental health worsens they may be unable to adhere to their treatment plans with worse outcomes all round.

She also remarked on the lack of dedicated support groups for LGBTQ people affected by cancer and said that Macmillan is working to develop those within the community.

Q4: How can cancer services and support excel at being LGBTQ inclusive?

Emma said: "Every cancer clinician and primary care practitioner should have mandatory LGBTQ awareness/Equality and Diversity training: training by the community and for the community."

She suggested that Clinical Nurse Specialists could send out questions to LGBTQ people the week before their meetings so that the conversations could really focus on their particular needs, and they could openly discuss any potentially difficult issues, such as sexual health, that had been raised in writing.

Emma felt that cancer services should reach out into LGBTQ communities with targeted information to raise awareness about cancer. For Emma, it is essential that education is a collaborative effort that involves LGBTQ people affected by cancer. Personal stories of LGBTQ people affected by cancer should be part of awareness-raising, and LGBTQ people affected by cancer should be involved in co-producing cancer-awareness literature and resources. This work should be a combined professional-community effort with Champions linking in with both. Advocacy and Navigator roles could support links between services and the community, in particular perhaps with hospital transport and bereavement services. This type of professional-community collaboration should be applied to all protected characteristics in Emma's opinion.

Cancer services would be improved, Emma believes, if LGBTQ people affected by cancer didn't have to continuously 'come out' to their professionals and then manage those professionals' responses. She remarked that this could "make the difference between being confident and being destroyed and vulnerable."

Emma described the 'emotional labour' incumbent on LGBTQ people to manage others' responses to their disclosure of their LGBTQ identities, and to educate their healthcare professionals of their needs and preferences. To do so is tiring and shouldn't be required of people when they are in a vulnerable position.

5. FINDINGS: FOCUS GROUPS

Focus group facilitators:

Chris Brown, LGBTQ Development Officer, Brighton & Hove LGBT Switchboard

Richard Longrigg, Partnership Quality Lead, East Surrey and Sussex, Macmillan Cancer Support

5.1 FIRST FOCUS GROUP: LGBTQ PEOPLE AFFECTED BY CANCER

Present:

- Person A (bisexual woman)
- Person B (lesbian)
- Person C (lesbian)

Participants' experiences with cancer

Person C was diagnosed and treated for breast cancer over 20 years ago and underwent a mastectomy and chemotherapy, with reconstruction 1 year later. She accessed support through family, medics and Macmillan Nurse and was subsequently diagnosed with skin cancer which was treated successfully. She had an appendectomy in 2016 and through scans discovered nodules on her lungs which were removed. She says the support she received throughout was very good and cannot fault it. Person C had previously run a breast cancer support group which had a specific focus on fundraising so she decided it wasn't the right group for her; she strongly feels that people need to access support through groups.

Person B was treated for uterine cancer herself, and her partner had ovarian cancer, which was the biggest journey that Person B wanted to share. They had a very poor experience with their GP, who Person B's partner visited a number of times in 2016 presenting with symptoms. The GP stated that Person B's partner was low risk for cancer due to not having children, due to her age (47 at the time of her diagnosis and subsequent death) and because she was not taking the contraceptive pill.

Person B's partner was diagnosed through A&E at an advanced stage. She underwent surgery in April discovering the cancer had spread to her bowel resulting in a stoma. She underwent double chemo treatment and started receiving palliative care. It was very difficult for Person B and her partner to get hold of the gynaecological Macmillan Nurse but when they did, she was amazing and put them in contact with Martletts Hospice. The partner's cancer subsequently spread to her liver, spleen and brain and she went into End of Life care. The partner saw a specific CNS three times prior to the final hospital admission and was also seen by a Macmillan palliative care consultant and CNS several times the day before she died. The doctor supported Person B 'massively' and was involved in decisions made; the doctor made a point of stating that as partner, Person B had a right to be involved. Person B's partner passed away the following morning.

Person B feels that much more could have been done earlier through the GP which would have had a significant impact on the outcomes for her partner. She had been told that had a diagnosis been given a month sooner, her partner would still be alive today. A pauper's funeral was held for Person B's partner.

Person B commented that The Cancer Centre (Brighton), Macmillan and Martletts were all brilliant. They always referred to her as the partner, and after her partner's death, Martletts also provided counselling for Person B.

Person A's sister was diagnosed with advanced and aggressive Breast Cancer in 1994 and died in 1998. Person A identifies as bisexual and her partner is a transgender male who identifies as bisexual; they both always associate themselves with the queer community. Person A was herself diagnosed with breast cancer in October 2016, and underwent a mastectomy, chemo and radiotherapy; she has lymphedema. Person A and her partner's sexual orientation wasn't disclosed to healthcare professionals at the time, and this didn't bother them, but Person A says that with hindsight, she would have liked this to have been acknowledged. They do not have a large social network or family but made a very close friend who was also receiving radiotherapy at the time.

Person A feels it would have been good to have the opportunity to access an LGBTQ support group – not to segregate but in order to connect with people with similar experiences.

In her treatment at Eastbourne Hospital Person A thought professionals were quite small-minded compared to those at Brighton. She commented that Macmillan nurses at Eastbourne were not easy to contact and she did not feel very supported by them. She said that The Horizon Centre has been amazing, as has the Macmillan Counselling service at Eastbourne. Person A is still receiving hormone treatment.

Was your sexual orientation, gender identity or sexual orientation monitored at any points during your cancer care pathway?

All three participants said no.

Person B and her partner were recognised by professionals as being a couple but were occasionally mistaken for mother and daughter. Person B was fully involved in making decisions about her partner's care, which was particularly useful when her partner was experiencing brain fog as a result of morphine. They both felt it important to be open about their sexual orientation and relationship.

Person C says her partner was welcome at hospital, but she also noted 'not wanting to make waves' in relation to disclosing her sexual orientation.

Person A only disclosed her sexual orientation to her Macmillan counsellor. She was frustrated by, on a number of occasions, receiving letters with the salutation 'Mrs' although she was not married. The assumption was made that she was married because she had a male partner. Letters were also written to her partner assuming that he was her husband. She said it had been assumed that they were a heterosexual nuclear family and that 'little things like that make you feel overlooked.' Person A said she didn't disclose her bisexuality at the time, partly as she felt shy, and 'had bigger fish to fry' but also because she was uncertain of the reaction she would have received. She said that if she had the experience over again she might be 'more upfront' and come out.

Were you given the name of a Clinical Nurse Specialist [CNS] who would support you through your treatment?

Person A was allocated two part-time Clinical Nurse Specialists. She recalled that when she had an onset of lymphedema this was initially dismissed as post-surgery swelling by a nurse, which made

things worse. However, she felt that she didn't want to bother them. She commented that she understands that nurses vary from facility to facility.

Person B said that her partner only saw a CNS three times. Her partner never attended The Horizon Centre but Person B believes she would have had a closer relationship with her nurse if she did so. Person B believes there's a need for more Macmillan nurses but doesn't want them to be stretched as they are so specialist, and Person A stated that more CNS are needed for each cancer group. All participants agreed that Macmillan nurses are essential. Person C said that they are particularly essential for patients' mental health and wellbeing, which really affects their outcomes. For this reason, she felt that they need to be open to supporting LGBTQ people with their needs.

All participants agreed it would help if cancer healthcare professionals who were LGBTQ felt comfortable to openly disclose their identities in some way, to help LGBTQ patients feel safer to disclose their own identities.

Were you given information about support groups for people with cancer?

Two participants were given information and one was not.

Would it be helpful to be able to go to LGBTQ cancer support groups?

All three participants said yes, it would, and discussed how such groups would be helpful.

One person commented that LGBTQ support groups would make the path easier and build confidence in receiving care. Person B observed that 'as a community we see our bodies differently to straight people,' and felt that there are issues different for LGBTQ people regarding their body image post-surgery: 'the impact is different – there are very big differences.'

Person C remarked that despite Brighton being a very accepting City, LGBTQ abuse and incidents still occur; LGBTQ people experiencing cancer have a 'double whammy' and with an impact 'like ripples in the pond'.

Person A has previously had some experience in a role where hate crimes were reported and picked up on, and she noted that any hate crimes should be reported, and that this is something Macmillan could promote.

Person C observed that, regarding intimacy, it's difficult for other [non-LGBTQ] people to understand or get their head around how or why cancer would affect an LGBTQ couple's intimacy.

Person B did ask healthcare professional about returning to sexual activity but her question was avoided. She felt that more sensitivity is needed by doctors when being asked this question.

Person A said that for trans men, there needs to be greater awareness where breast cancer has been experienced, noting that 'things may go under the radar' with trans peoples' initial diagnoses.

Were you treated with dignity and respect?

- Yes x 3
- Person B also felt that her partner would have responded to this question with a yes.

On a scale of 0 - 10 scale, how would you rate the overall care you received from the NHS?

People B and C each gave a score of 9, with Person B saying she felt her partner would have given a rating of 7. Person A gave a score of 7.

Have you experienced any barriers in accessing cancer treatment, support and/or information?

Person B spoke further about her and her partner's experiences with their GP, and the fact that the GP told her partner that she was not at risk for cancer because she had not had children and did not have penis-in-vagina sex. Person B has been told that if her partner had been diagnosed sooner 'she would still be here'. The same doctor refused her partner pain relief at home and they raised a formal complaint about this. Person B felt that the GP had an issue with her personally because her experience as an advocate around health issues.

Person B spoke of her own experience with cancer and being told she had to have repeated pregnancy tests, although she explained that as a lesbian the tests were unnecessary. She said the repeated requests were 'like a smack in the face' regarding the fact that she does not have children. She wondered if the same question would be asked repeatedly of single women. She said that a common barrier for lesbians is being told that they don't need cervical screening.

Person A spoke of feeling invisible as a bisexual woman with a male, bisexual partner. She wasn't aware of experiencing direct inequalities but imagined this could have been different if she had a same sex partner. Person A had some problems with letters received from the NHS detailing the wrong grade and size of tumour. She was treated on the correct pathology but every single letter, including those to her GP, was wrong. She also described an experience where she was receiving treatment through a picc line and the cap failed. Person A felt that these errors indicate inefficiency and a lack of funding.

If you could, what would you make possible/change in terms of cancer information, care and support for LGBTQ people?

The focus group members came up with several suggestions:

- Bringing in an LGBTQ Macmillan nurse specialist role/champion – somebody who is identifiable as LGBTQ
- Increasing recognition and awareness of LGBTQ issues in primary care, particularly for GPs
- Introducing LGBTQ awareness training for all nurses/people who come into contact with people affected by cancer – this should be mandatory training for all healthcare professionals
- Improving visual imagery, posters and suchlike by making them broader and more inclusive
- Giving information packs/leaflets to all people when diagnosed with cancer, including a contact list of other support available
- Developing websites, phone helplines etc. specifically for LGBTQ people with cancer.
- Developing LGBTQ-specific support groups for people affected by cancer [all participants confirmed they are happy to be contacted by Macmillan if a group is established]

Postscript:

Following the focus group, all three participants commented by email on the value of being part of the focus group. One person wrote (and has given permission for her comments to be shared):

Thanks for organising the focus group, The venue was great and you and Richard made us feel very comfortable and able discuss our experience's and cancer journey's.

The meeting brought up many worthwhile issues that maybe in our busy lives are not at the forefront of our minds but have had an effect on our wellbeing. You asked for comments, so here are mine.

Would it be possible to hold monthly Focus Group Meeting in order to update on progress and further develop action plans. Also it would be great if we invite a trans person, a gay guy and anyone else from the LGBTQ community. This would give wider information regarding the issues which need to be addressed.

I am happy to help in any way.

5.2 SECOND FOCUS GROUP: PROFESSIONALS INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Present:

- Nikki Kettley: Information Services Manager, Walk-In Information and Support (The Horizon Centre); trained as a cancer nurse.
- Carolyn Phelps: Project Assistant Coordinator, Speak Up Against Cancer (part of the Health Team at Albion in the Community)

How often do you come into contact with LGBTQ+ people affected by cancer in your work?

Both participants come into contact with LGBTQ community members through their services and projects on a day-to-day basis. LGBTQ people regularly visit The Horizon Centre, which provides an open space for people to talk 1:1 with a worker about the issues on their minds, which may include cancer treatment and HIV, sex and relationship support. The Information Services Manager felt from her own experience that up to three people per week may be LGBTQ. The Horizon Centre doesn't routinely collect LGBTQ monitoring information as it would be on a one-to-one basis with a client that this information might be shared.

The Information Services Manager sometimes uses a Support Needs Assessment tool in 1:1 appointments with clients (this is not the same as the Holistic Needs Assessment used by healthcare professionals), which doesn't have a question on it specifically about sexual orientation but offers an opportunity for clients to identify if they'd like to discuss sexual concerns or relationships. The Centre is developing monitoring systems which will provide a snapshot of visitors at specific times of the year. Some service users may disclose their sexual orientation, gender identity or trans status in 1:1 conversations with staff.

Speak Up Against Cancer engages through outreach work in the community to raise awareness of the signs and symptoms of cancer and has links with local LGBTQ organisations, holding specific awareness-raising events in partnership with them.

In general, how confident do you feel in providing support (clinical or emotional, or providing information, signposting, etc.) to LGBTQ patients and their carers?

Speak Up Against Cancer has 20+ volunteers and LGBTQ awareness is not included in their training, so there are varying levels of confidence. Lived experience with cancer, and good communication skills, are the main priorities in volunteer selection. The staff team feels confident.

The Horizon Centre uses information and support volunteers chosen for their communication and interpersonal skills but would not expect to have specialist information or support. The Information Services Manager is very confident in supporting LGBTQ patients and carers. Signposting service users to relevant information and support is key to her role.

Areas focus group members are less confident in:

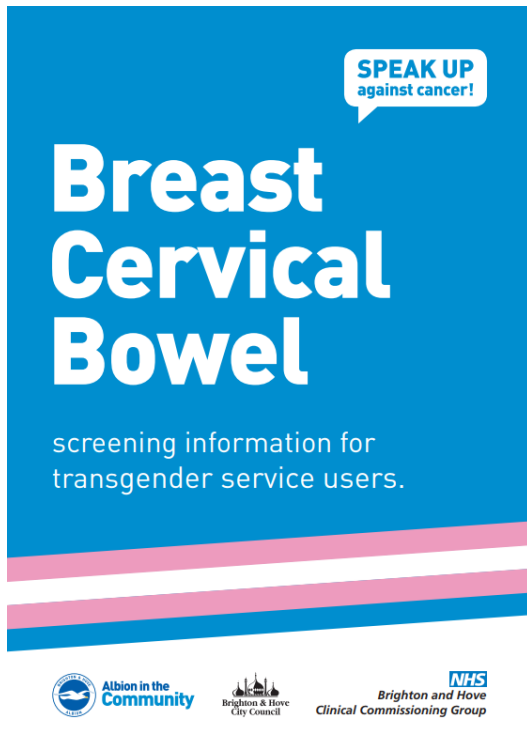
It was recognised by Nikki that “Not everybody is comfortable talking about private parts.” Use of the Support Needs Assessment tool is useful in flagging up taboo or complex issues that a patient may later come back to in conversation. Cancer nurses have an important role in opening up conversations about people’s needs and identities. Some patients may struggle to talk about sexual function and sexual relationships, so a person-centred approach can help create the conditions for disclosure.

Some volunteers at Speak Up Against Cancer feel uncomfortable asking people about their sexual orientation, and are concerned about causing offense by doing so, which could be the result of a lack of confidence in supporting LGBTQ people. It’s useful to be aware of, for example, diverse relationship types. Both participants agreed strongly that it is important to create the right environment to hold these conversations.

Do you consider an understanding of someone’s sexual orientation and/or gender identity to be important in delivering best possible cancer care? Why/why not?

The Horizon Centre’s Information Services Manager feels it is important to have an awareness of people’s diverse differences and needs, but overall “people are people” who may have concerns about diverse issues including welfare or relationships. She noted that many patients talk about their relationships, so it’s useful to know about diverse types of relationship. She also commented that she had had feedback from an LGBTQ patient that they felt there was a lack of LGBTQ representation in the information leaflets on display in The Horizon Centre. Her role focuses on signposting patients to the information and support that is relevant to them.

Speak Up Against Cancer’s Project Assistant Coordinator noted that being aware of a person’s LGBTQ identity can help with building rapport. She felt it was particularly important to be aware of trans people’s needs in order to give them the right screening information, for example prostate screening information to trans women and cervical screening information to trans men who have a cervix.



Both feel Albion in the Community’s [‘Breast Cervical Bowel Cancer: screening information for transgender service users’](#) leaflet is a very good resource. The Horizon Centre mainly supports people when they receive their diagnosis, or post-diagnosis.

Speak Up Against Cancer’s Project Assistant Coordinator noted that some lesbians are reluctant to attend cervical screening due to an assumption that lesbian women do not need to; she was not clear where this misunderstanding is coming from.

The Horizon Centre’s Information Services Manager commented that this assumption reflects her previous experience of working with a cancer support helpline; an example being a caller’s concerns that cervical cancer is contagious through sexual contact.

Would you like to access further training, support or information in regards to working with LGBTQ patients with cancer? If so, what would be helpful?

Speak Up Against Cancer’s Project Assistant Coordinator hadn’t asked her volunteers about their confidence in responding to LGBTQ, but felt that general LGBTQ awareness training for volunteers would be very useful, especially as language is evolving in relation to sexual orientation and gender identity issues.

The Horizon Centre’s Information Services Manager has been proactive and self-educating and agrees that LGBTQ awareness training for volunteers would be useful as it would generate a better understanding of the issues faced by LGBTQ patients. In general, inclusion fits within the aims of The Horizon Centre.

In your experience, what (if any) barriers do LGBTQ people experience in accessing cancer treatment, support and/or information?

The Horizon Centre’s Information Services Manager noted that cancer is a difficult subject in itself, and that many people find it hard to walk into the centre to seek help; she wondered if it might be more difficult for LGBTQ people. She felt that there was a lack of LGBTQ images and representation in information and that generally information sources, including Macmillan resources, needed images that seem more relevant. The Services Manager also commented that she has had enquiries about LGBTQ-specific cancer support groups and has signposted to Macmillan’s online LGBT Lounge community.

Speak Up Against Cancer’s Project Assistant Coordinator felt that older people in the LGBTQ community may be more hesitant to discuss their LGBTQ identities, or sensitive issues including, for example, erectile dysfunction. She has had feedback from a few LGBTQ people that they often feel that the posters/information in GP surgeries simply didn’t relate to them, and that they would probably actively seek out LGBTQ-specific information and resources if available.

[At the end of responses to this question the facilitators outlined research describing some of the most common barriers experienced by LGBTQ people affected by cancer.]

What would you like to see being done to improve access and inclusion for LGBTQ+ people affected by cancer?

Speak Up Against Cancer want to do more work to bring cancer awareness into LGBTQ communities to increase understanding of the signs and symptoms of cancer and the need for screening. The organisation would like to hold more specific/dedicated events for LGBTQ people alongside generic events. They are currently working with Public Health Brighton & Hove to source LGBTQ signposting information for their website and will continue to distribute their trans-inclusive screening leaflet.

The Horizon Centre's Information Services Manager imagined that LGBTQ-specific literature would be picked up at the drop in and would encourage open conversations about LGBTQ-related needs; she will think about how to integrate this material with existing resources. She was also keen for the Centre to improve and expand their monitoring to include asking about LGBTQ identities, as they currently only monitor ethnicity and age. This would help to identify needs earlier on so that more relevant information can be provided. The Services Manager also discussed an LGBTQ-inclusive statement for their service leaflet, perhaps as part of a broader inclusion statement. She felt that while this would be good, it wouldn't necessarily be a simple solution.

At the end of the session both participants commented positively on the value of the focus group for raising questions about how to improve access to information and support for LGBTQ people affected by cancer.

6. FINDINGS OF INTERNET SURVEY: PROFESSIONALS AND VOLUNTEERS INVOLVED IN SUPPORTING PEOPLE AFFECTED BY CANCER

Participants were all first presented with an initial screening question, which limited the sample, by self-exclusion of participants who did not meet certain criteria. The screening question limited the sample to *'This survey is specifically for professionals and volunteers involved in supporting people affected by cancer.'* After this question, there were a total of 35 eligible respondents. At the end of the survey, data was collected on participants' age, sexual orientation, gender identity, trans status, ethnicity and disability.

6.1 JOB ROLES (34 respondents)

Participants were asked to select their roles from a drop-down list. Their responses were categorised as follows:

- **Clinical Nurse Specialist:** 24% (8)
- **Support Worker:** 15% (5)
- **Psychological Service/Counsellor:** 12% (4)
- **Radiographer:** 3% (1)

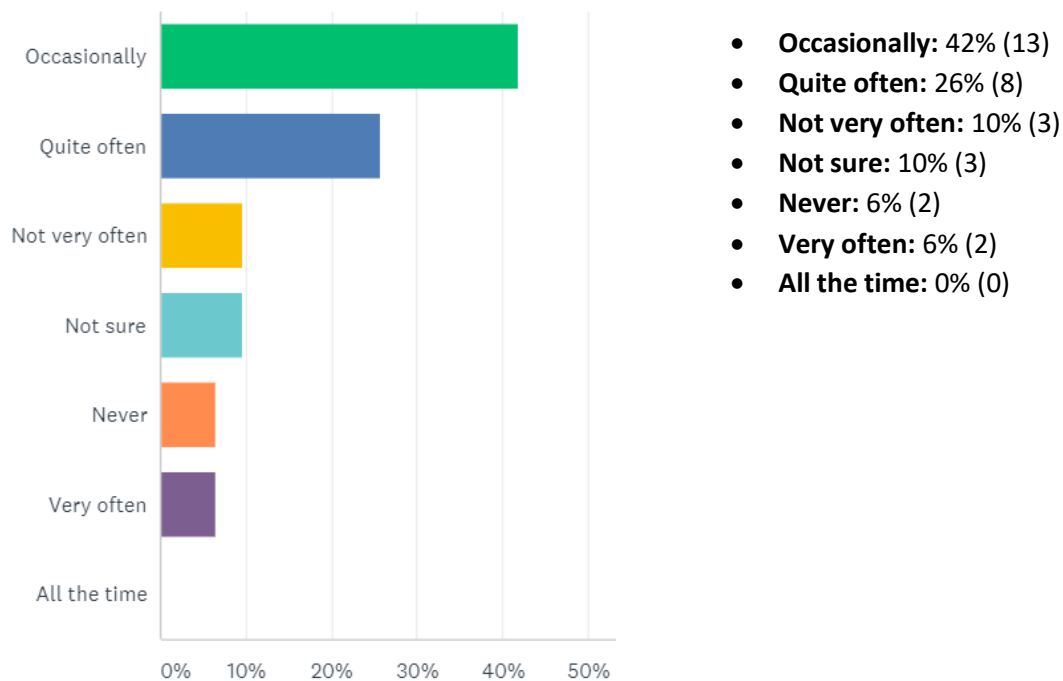
47% (16) of respondents selected 'Other.' Specific role descriptions detailed in the comments are as follows:

- 2 x volunteers in the Horizon Centre Café
- Café support
- Volunteer Pilates teacher
- Non-NHS Support Service

- Volunteer - physical therapies
- Volunteer Acupuncturist
- Massage Therapist
- Support and information volunteer
- Volunteer
- Dance teacher
- Head and Neck Cancer Buddy Volunteer

6.2 FREQUENCY OF CONTACT WITH LGBTQ PEOPLE AFFECTED BY CANCER (31 respondents)

Participants were asked ‘How frequently in your work with people affected by cancer, are you aware of coming in contact with any patients who are from the LGBTQ community?’ Their responses are detailed below in descending order.



Given the opportunity to do so, five respondents commented on the question. Comments included:

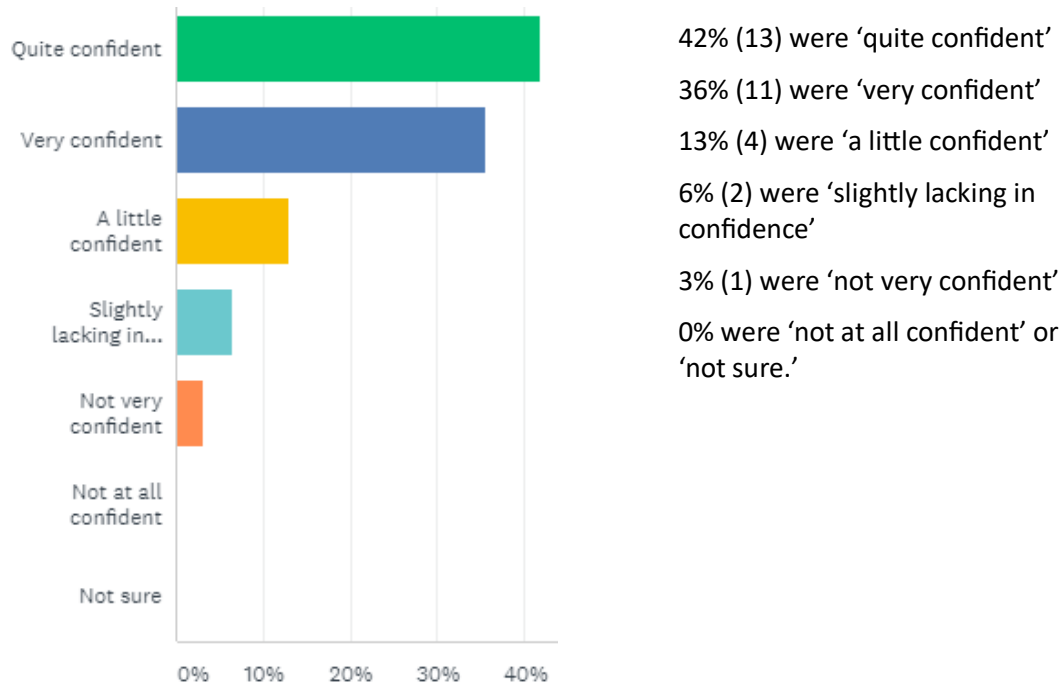
“ This is not something that I would specifically ask or seek to discover, but sometimes it would become apparent in discussion.”

“ Maybe I come into contact with LGBTQ people with cancer more than I realise?”

6.3 CONFIDENCE IN PROVIDING SUPPORT TO LGBTQ PATIENTS AND THEIR CARERS (31 respondents)

Participants were asked: *'In general, how confident do you feel in providing support (clinical or emotional, or providing information, signposting, etc.) to LGBTQ patients and their carers?'*

The majority of respondents were 'quite' or 'very' confident as detailed below.



Seven respondents commented on their answers. One respondent felt that knowing a person's LGBTQ identity was irrelevant to providing them with support. Other comments included:

“ I feel no more or less confident in these cases than in any other cases. In all cases I focus primarily on the person's needs as an individual and as a person affected by cancer. If they have specific questions or concerns relating to the implications of their sexuality or sexual orientation, then I would respond to these, in the same way that I would respond to a heterosexual person presenting with similar questions for concerns

“ Would welcome further training.”

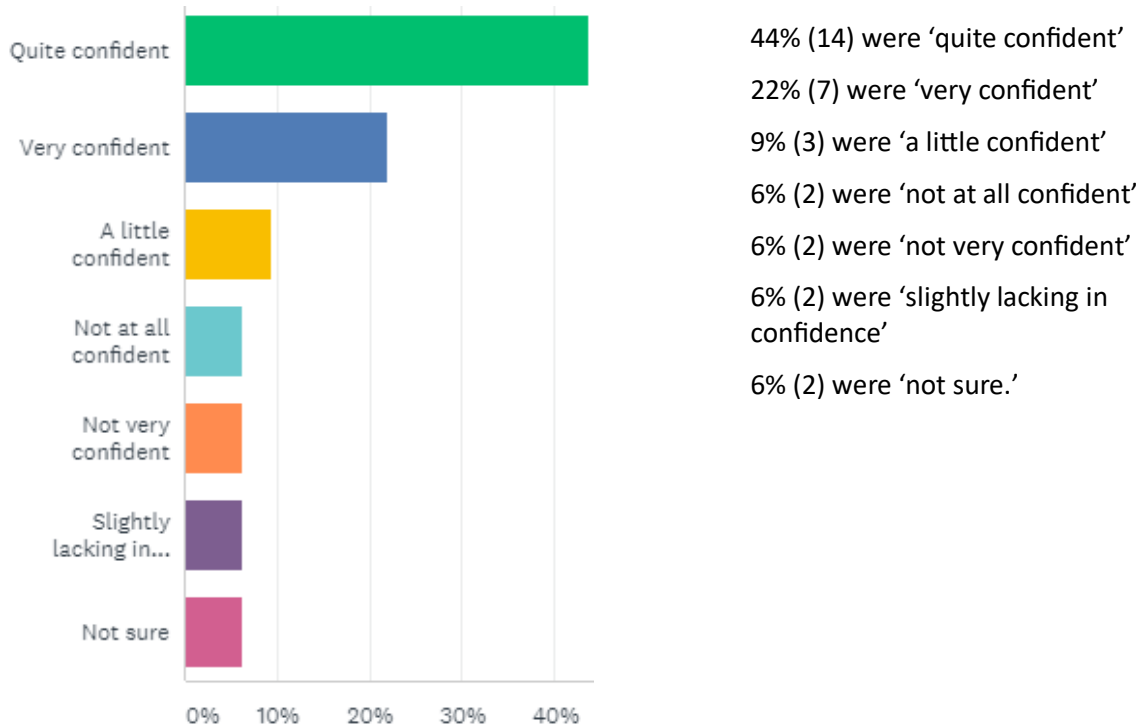
6.4 CONFIDENCE IN ACKNOWLEDGING THE NEEDS OF AND PROVIDING SUPPORT TO TRANSGENDER PATIENTS (32 respondents)

Participants were asked: *'In general, how confident do you feel about acknowledging the needs of and providing support to transgender patients (those whose gender identity is different from the gender they were assigned at birth)?'*

As with the previous question, the majority of respondents were 'quite' or 'very' confident. However, confidence levels were overall lower for supporting transgender people than supporting LGBTQ people as a whole. Two comments indicated a desire for trans awareness training, including a person who commented:

“ Would welcome further training.”

“ Though i feel confident myself i do not feel that as a trust we do enough to support transgender patients, and i feel this has a lot to do with training.”



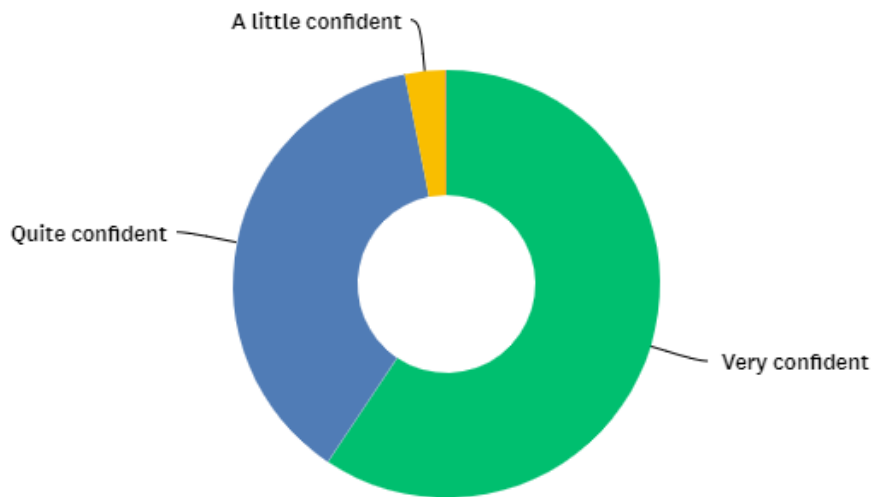
6.5 CONFIDENCE IN SUPPORTING THE NEEDS OF SAME SEX COUPLES (32 respondents)

Participants were asked: ‘How confident do you feel in supporting the needs of same sex couples (e.g. being able to acknowledge their partners as partners, and not friends or general family members)?’

Confidence levels were highest for this question than in the previous two, with no respondents saying that they were not at all/not very confident, or slightly lacking in confidence.

One person commented:

“ All people affected by cancer (cancer patients, their relatives, partners, friends, carers and family members) are responded to in the same way - i.e. we look at their needs and concerns as individuals.”

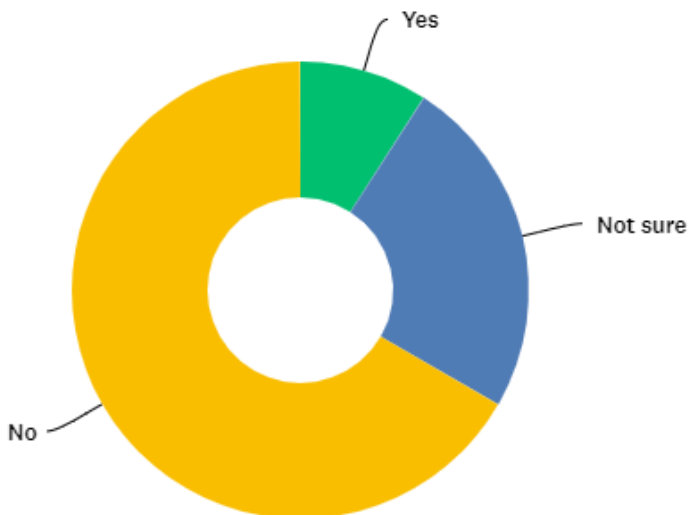


59% (19) were 'very confident'
 38% (12) were 'quite confident'
 3% (1) were 'a little confident'
 0% were 'not at all confident'
 0% were 'not very confident'
 0% were 'slightly lacking in confidence'

6.6 MONITORING SEXUAL ORIENTATION (33 respondents)

Participants were asked: 'Do you regularly monitor the sexual orientation of patients/clients/service users in your service or department?'

The majority of respondents do not monitor sexual orientation.



67% (22) do not monitor sexual orientation
 24% (8) are unsure whether they monitor sexual orientation
 9% (3) do monitor sexual orientation

Of the six people who commented here, two felt that it was not important to ask about sexual orientation and three felt that patients would disclose if they wanted to. Comments included:

“ The only relevant criterion to providing the service is that someone should be affected by cancer in some way. If they wish to disclose their sexual orientation (e.g. because they see it as

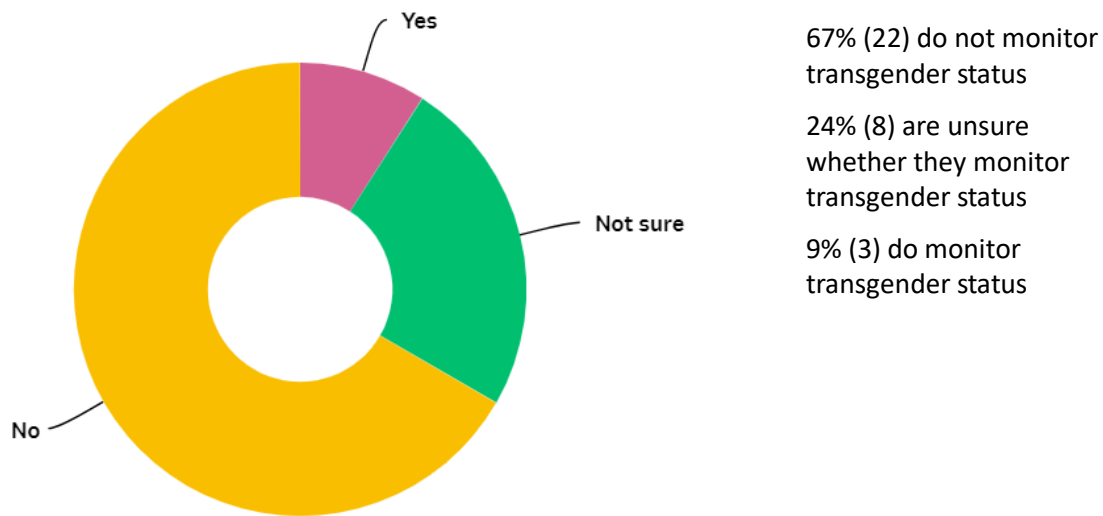
relevant to their needs or the reasons they wish to use the service), that's for them to volunteer. I would not ask them about it proactively.”

“ No we don't because it makes no difference at all about how these patients are cared for..”

6.7 MONITORING TRANSGENDER STATUS (33 respondents)

Participants were asked: ‘Do you regularly monitor whether patients/clients/service users in your service or department are transgender?’

The majority of respondents do not monitor transgender status.

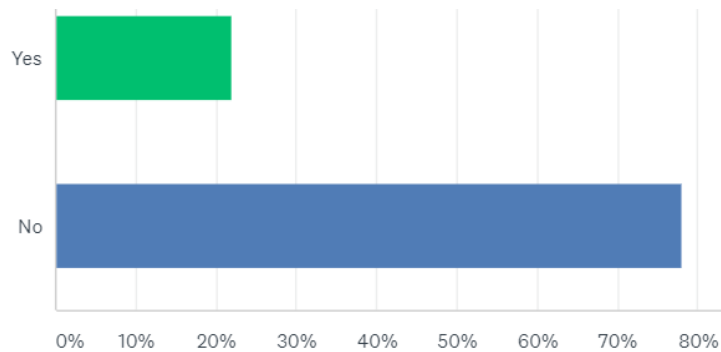


Three people commented; two felt that monitoring was unnecessary for reasons cited in the previous question and one said that they had ‘Not experienced a transgender patient yet.’

6.8 PREVIOUS LGBTQ AWARENESS INFORMATION AND/OR TRAINING (32 respondents)

Participants were asked: ‘Have you received any information or training that you can draw on to help you support LGBTQ patients and their carers?’

22% (7) of respondents answered with a yes, and 78% (25) with a no.



When invited to comment, eight participants did so. Two had received some LGBTQ awareness training through Macmillan, and others had accessed some information or training through Opening Doors/Age UK, public sector employers, Prostate UK or Sussex Partnership NHS Foundation Trust. One person felt that general equalities training had been ‘[Helpful in stressing the importance of seeing the person not their social, gender, race or other 'category.'](#)’

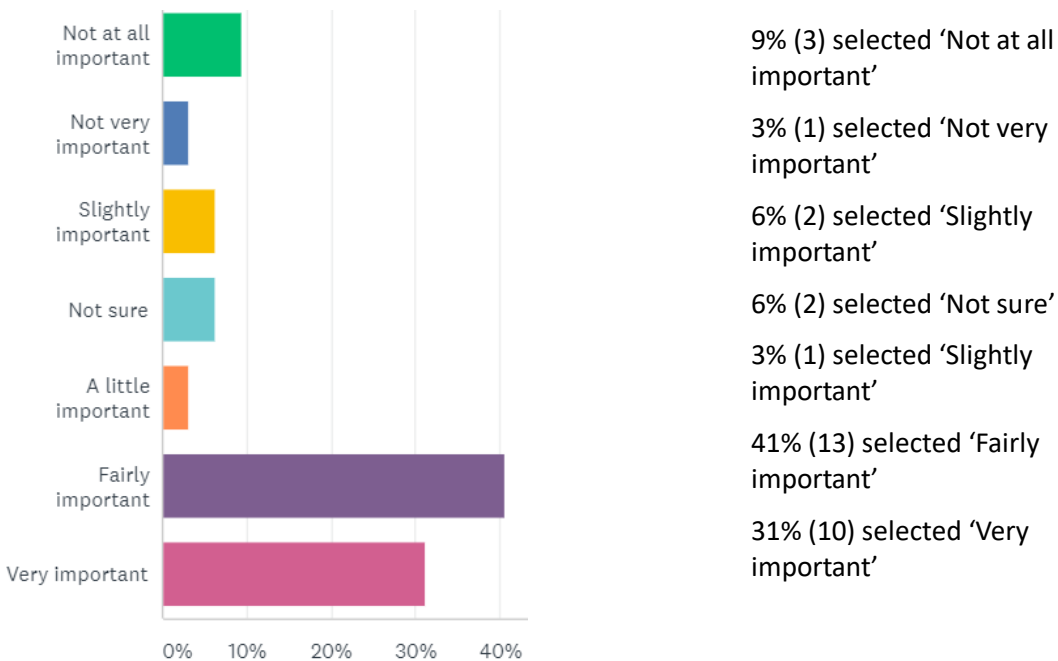
Other comments included:

- “ Though we do have equality and diversity training within our trust, this update is not regular and even though i am a member of the LGBTQ community i did not feel that when i last went to the training it was particularly beneficial.”
- “ Have done 2 lot of training since setting up the service in 2015. The first training was delivered by Opening Doors and Age UK and was for working with Older LGBT people. I found this excellent. The activities that were facilitated were very thought provoking and helped you to consider the peoples life course and how this may affect barriers to receiving effective services. The 2nd training was offered by Macmillan. The discussion with other professionals was quite interesting.”

6.9 IMPORTANCE OF UNDERSTANDING OF SOMEONE’S SEXUAL ORIENTATION AND/OR GENDER IDENTITY (32 respondents)

Participants were asked: ‘Do you consider an understanding of someone’s sexual orientation and/or gender identity to be important in delivering best possible cancer care?’

A combined total of 72% (23) felt that it was ‘fairly’ or ‘very’ important to have an understanding of someone’s sexual orientation and/or gender identity to be delivering the best possible cancer care.



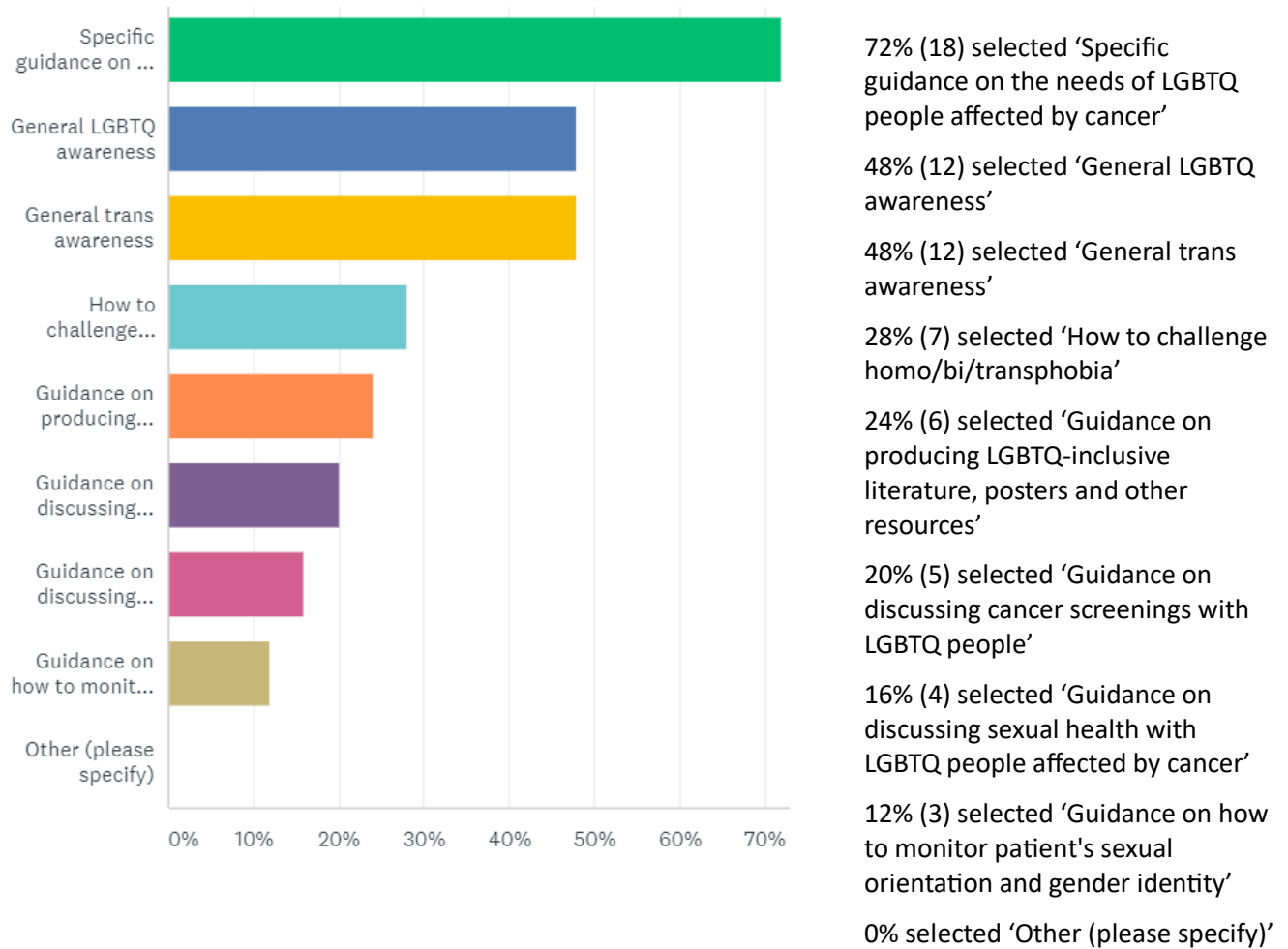
Seven respondents commented, with three saying that understanding someone's sexual orientation or gender identity is important to them if it's important to the patient. Comments included:

- “ The important thing is to have an awareness of the potential barriers to someone receiving an effective service so that you can meet the needs of the individual.”
- “ Yes, I do! Statutory services and even third sector services to a lesser extent tend to have a default cis-het approach/forms and also images in their comms and services which marginalise LGBTQ people and their family. It would make a service user feel fearful and wonder if it was a safe and queer-affirmative space. This is terrible, especially considering that the service user is already in a vulnerable place, for example, if they had cancer. I'm really surprised that this is still the case in 2018. I mean, I appreciate a rainbow sticker on the window but we need much more than that. It needs to travel into policy, staff training, imagery, events and more.”

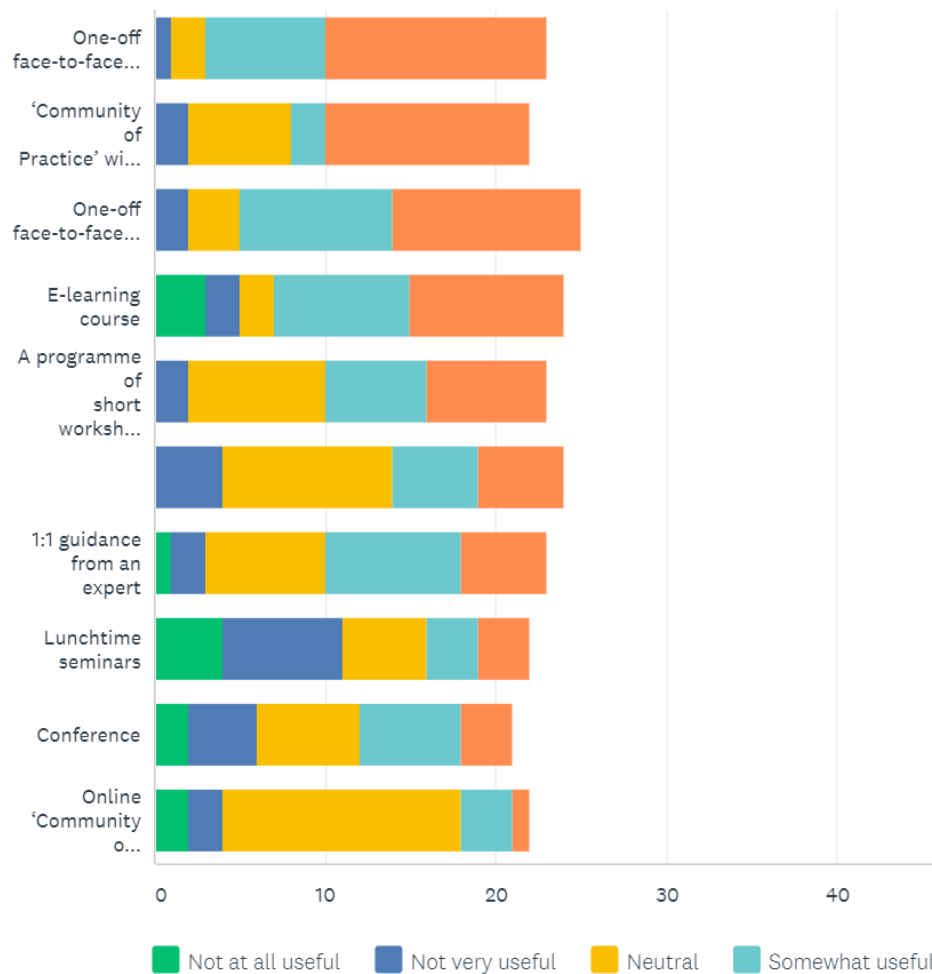
6.10 DESIRE FOR TRAINING, SUPPORT OR INFORMATION (33 respondents)

Participants were asked: 'Would you like to access further training, support or information in regards to working with LGBTQ patients with cancer?'

79% (26) of respondents replied with a Yes, and 21% (7) with a No. Of those 26 respondents who selected Yes, 25 went on to select the kind of content they would find helpful from a menu of choices.



The same 25 respondents were also asked *'How useful do you think the below options for training and support would be to you?'* (please tick one rating per idea in the table below). The results are as follows.



The options that respondents said would be **'Very useful,'** in descending order:

56% (13) selected 'One-off face-to-face in-house course'

55% (12) selected 'Community of Practice' with invited speakers (including LGBTQ people affected by cancer)

44% (11) selected 'One-off face-to-face open course'

38% (9) selected 'E-learning course'

32% (7) selected 'A programme of short workshops (in-house)'

22% (5) selected 'A programme of short workshops (open)'

22% (5) selected '1:1 guidance from an expert'

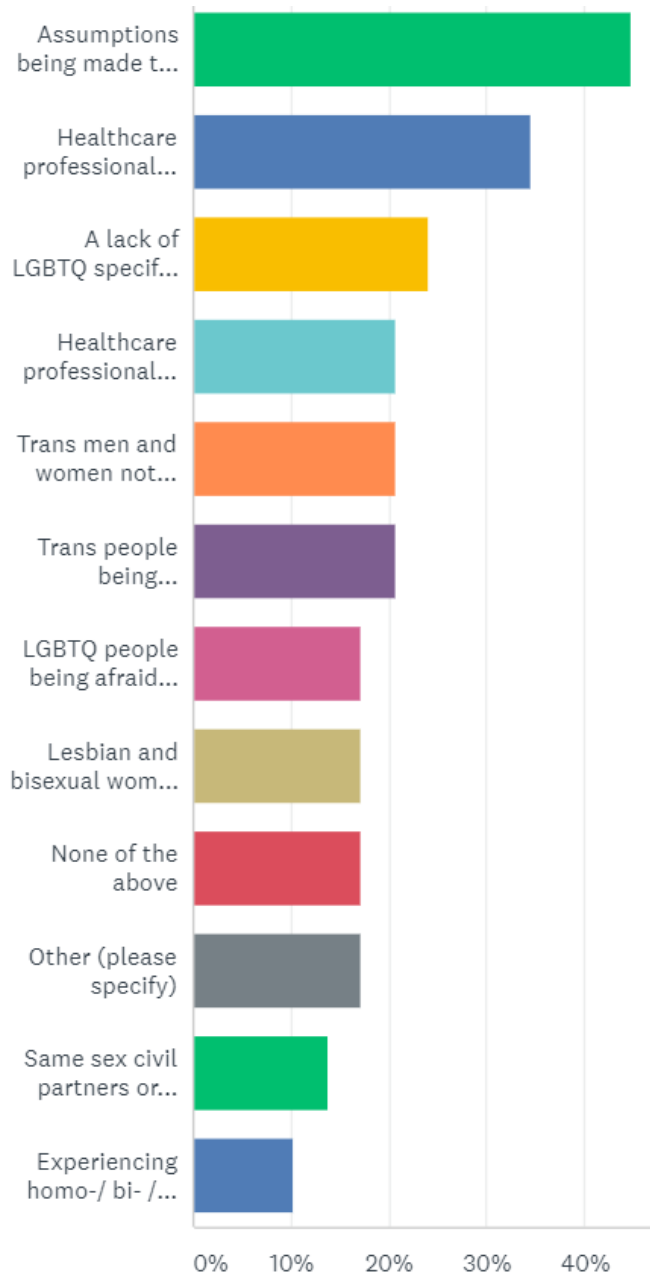
14% (3) selected 'Lunchtime seminars'

14% (3) selected 'Conference'

5% (1) selected 'Online 'Community of Practice'

6.11 BARRIERS FOR LGBTQ PATIENTS (29 respondents)

Participants were asked: 'In your experience, what (if any) barriers do LGBTQ people experience in accessing cancer treatment, support and/or information? Please select all that apply.'



45% (13) selected 'Assumptions being made that all patients are heterosexual and cisgendered (i.e. people whose experiences of their own gender agree with the sex they were assigned at birth)'

35% (10) selected 'Healthcare professionals not being LGBTQ-aware and inclusive'

24% (7) selected 'A lack of LGBTQ specific information and resources e.g. posters, leaflets'

21% (6) selected 'Healthcare professionals not being confident to discuss sexual health issues with LGBTQ people'

21% (6) selected 'Trans men and women not receiving relevant information about the need for cervical screening and prostate screening'

21% (6) selected 'Trans people being mis-gendered by professionals (referred to by a pronoun or form of address, that does not correctly reflect the gender with which they identify)'

17% (5) selected 'LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia'

17% (5) selected 'Lesbian and bisexual women being told they don't need to have cervical screening'

17% (5) selected 'None of the above'

14% (4) selected 'Same sex civil partners or spouses not being recognised as next of kin'

14% (4) selected 'Same sex civil partners or spouses not being recognised as next of kin'

10% (3) 'Experiencing homo-/ bi- / transphobia from professionals'

17% (5) of respondents to the question about barriers selected ‘Other – please specify.’ Four of these respondents said that either they lacked experience, they didn’t know or that they weren’t aware of any barriers. One respondent commented on potential barriers for people not in legally-accepted relationships:

“ Partners not being recognised as NOK [Next of Kin] - if those in legally recognised relationships aren't accepted then it concerns me what chance those who opt out of that institution (or who cannot be part of that due to poly set-up etc) have...”

7. FINDINGS OF INTERNET SURVEY: LGBTQ PEOPLE AFFECTED BY CANCER

Participants were all first presented with an initial screening question, which limited the sample, by self-exclusion of participants who did not meet certain criteria. The screening question was: *‘This survey is for LGBTQ (lesbian, gay, bisexual, transgender, queer or questioning) people in Brighton & Hove and Sussex who are affected by and living with cancer. This includes people affected by and living with cancer, and their partners, family members and friends. Does this describe you?’*

After this question, there were a total of 26 eligible respondents. These 26 people were asked *‘Are you a person who has been diagnosed with cancer, or a partner/family member/ friend of a person affected by cancer?’* 53% (9) of respondents had themselves been diagnosed with cancer, and 47% (8) were partners/family members/ friends of an LGBTQ person affected by cancer. Nobody belonged to both groups. Their data will be presented separately below.

At the end of the survey, data was collected on participants' age, sexual orientation, gender identity, trans status, ethnicity and disability.

7.1 HOW RESPONDENTS HAVE BEEN AFFECTED BY CANCER (9 respondents)

Participants were asked: *‘Please tell us a little more about how you are affected by cancer.’* They could select more than one option.

11% (1) said they had been diagnosed with cancer.

11% (1) said they were currently being treated for cancer.

89% (8) had completed treatment for cancer.

Nobody selected ‘I am living with incurable cancer’ or ‘I am receiving end of life care.’

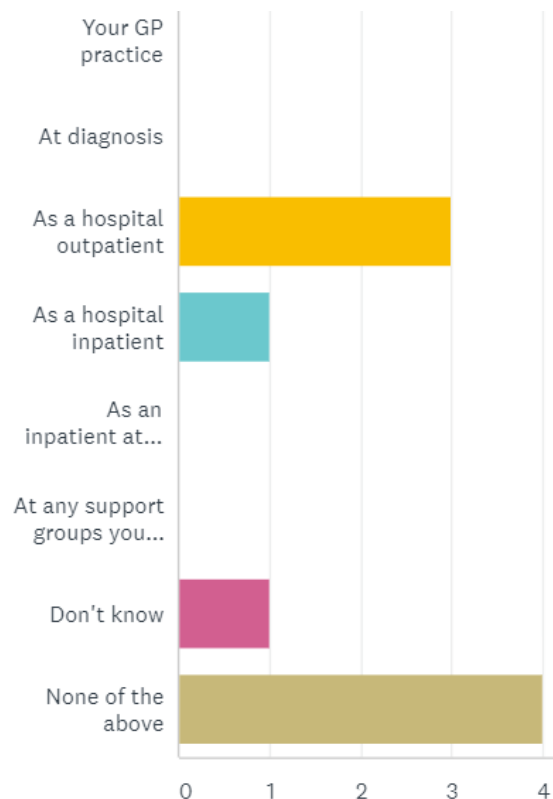
22% (2) participants selected ‘Other (please specify)’ but didn’t leave a comment.

ANSWER CHOICES	RESPONSES	
▼ I have been diagnosed with cancer	11.11%	1
▼ I am currently being treated for cancer	11.11%	1
▼ I have completed treatment for cancer	88.89%	8
▼ I am living with incurable cancer	0.00%	0
▼ I am receiving end of life care	0.00%	0
▼ Other (please specify)	Responses 22.22%	2

7.2 MONITORING FOR SEXUAL ORIENTATION, GENDER IDENTITY AND TRANS STATUS (9 respondents)

Participants were asked: 'Was your sexual orientation (e.g. lesbian, gay, bisexual) monitored at the following points? Please select all that apply.' They could select more than one option. The same question was repeated for gender identity and trans status.

Sexual orientation monitoring: (9 respondents)



33% (3) had their sexual orientation monitored as hospital outpatients

11% (1) had their sexual orientation monitored as hospital inpatients

11% (1) selected 'Don't know.'

44% (4) selected "None of the above"

0% reported their sexual orientation being monitored at their GP practice, at diagnosis, as an inpatient an inpatient at a different facility e.g. hospice or at any support groups

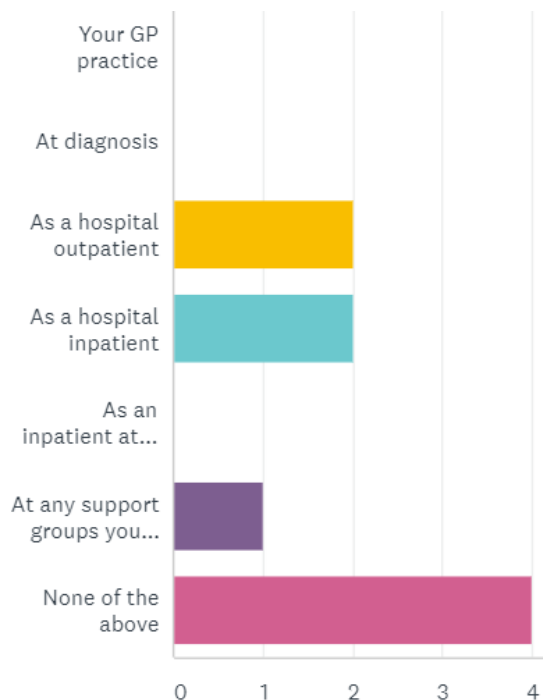
Comparison with partner/family member/friend's answers (3 respondents)

33% (1) said their partner/family/friend's sexual orientation was monitored as a hospital inpatient

33% (1) said they didn't know

33% (1) selected 'None of the above'

Gender identity monitoring: (9 respondents)



22% (2) had their gender identity monitored as hospital outpatients

22% (2) had their gender identity monitored as hospital inpatients

11% (1) had their gender identity monitored at any support groups they attended

44% (4) selected 'None of the above'

0% reported their gender identity being monitored at their GP practice, at diagnosis, as an inpatient an inpatient at a different facility e.g. hospice or at any support groups

One person commented that their gender identity was monitored by 'All who were involved with treatment,' and a second person noted that 'Records regarding gender identity exist at all of the above situations.'

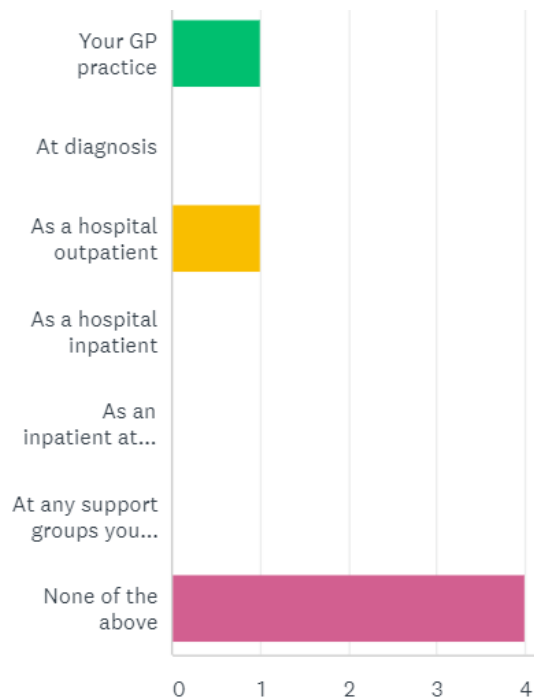
Comparison with partner/family member/friend's answers (3 respondents)

67% (2) said they didn't know if/when their loved one's gender identity was monitored

33% (1) selected 'None of the above'

Trans status monitoring: (6 respondents)

Participants were asked, 'Was your trans status (e.g. whether you identify - or have ever identified - as trans, non-binary) monitored at the following points? Please select all that apply.'



11% (1) had their trans status monitored at their GP practice

11% (1) had their trans status monitored as hospital outpatients

44% (4) selected "None of the above"

0% reported their trans status being monitored at diagnosis, as an inpatient an inpatient at a different facility e.g. hospice or at any support groups

Comparison with partner/family member/friend's answers (3 respondents)

67% (2) said they didn't know if/when their loved one's trans status was monitored

33% (1) selected 'None of the above'

7.3 TIME WAITED FOR DIAGNOSTIC TEST (9 respondents)

Participants were asked: 'Overall, how did you feel about the length of time you had to wait for your diagnostic test to be done?'

78% (7) answered that 'it was about right.' 22% (2) said that it was 'a little too long.' Nobody selected 'it was much too long' or 'don't know/can't remember.'

One person commented that they'd had 'Two weeks between diagnosis and operation. Excellent!' Another reported a two-week period in spite of an initial problem:

“ Myself and my partner had to chase up the 'two week wait' referral, as a GP had their written referral returned due to inadequate information and incorrect processes. (She was a new doctor & I appreciated that she attempted to refer my symptoms in the first place). Practice manager became involved in re-submitting the initial referral - which eventually fell exactly at the two week period.”

Comparison with partner/family member/friend's answers (3 respondents)

33% (1) selected 'It was about right'

33% (1) selected 'It was a little too long'

33% (1) selected 'It was much too long'

One person commented: "She went to GP 7/8 times before ending up in A&E, she spent 11.5 hour's there and was diagnosed there."

7.4 CLINICAL NURSE SPECIALISTS (9 respondents)

Participants were asked: *'Were you given the name of a Clinical Nurse Specialist [CNS] who would support you through your treatment?'*

67% (6) answered with a yes, and 33% (3) with a no. Nobody selected 'don't know/can't remember.'

One participant felt that they 'didn't need assistance,' while another person experienced some issues with the named Macmillan nurses they were allocated:

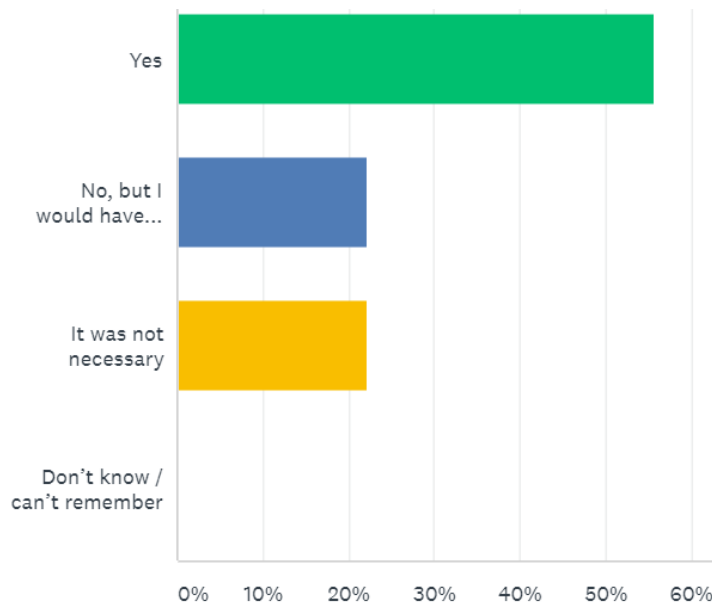
“ There were two named Macmillan nurses at the start of my surgery, but I must say that they were not so contactable or available as my treatment progressed beyond chemotherapy and radiotherapy. They were part time and I felt reluctant to request support / info as I felt hurried and a little dismissed by them in our conversations. I know this is not the experience at other hospitals, and I am aware that other patients t my hospital felt the same. Contrastingly, at a Moving Forward course in another hospital the (Non Macmillan) clinical nurse specialists appeared much more engaged and supportive.”

Comparison with partner/family member/friend's answers (3 respondents)

100% (3) of respondents said their partner/family member/friend was given the name of a CNS.

7.5 INFORMATION ABOUT SUPPORT GROUPS (9 respondents)

Participants were asked: *'Did you receive information about support or self-help groups for people with cancer?'*



56% (5) selected 'Yes.'

22% (2) selected 'No, but I would have liked to receive information.'

22% (2) selected 'It was not necessary.'

0% selected 'Don't know/can't remember.'

One respondent found the information themselves 'by browsing the leaflets and booklets on display in the Cancer Centre.' Another person found more than one source of information:

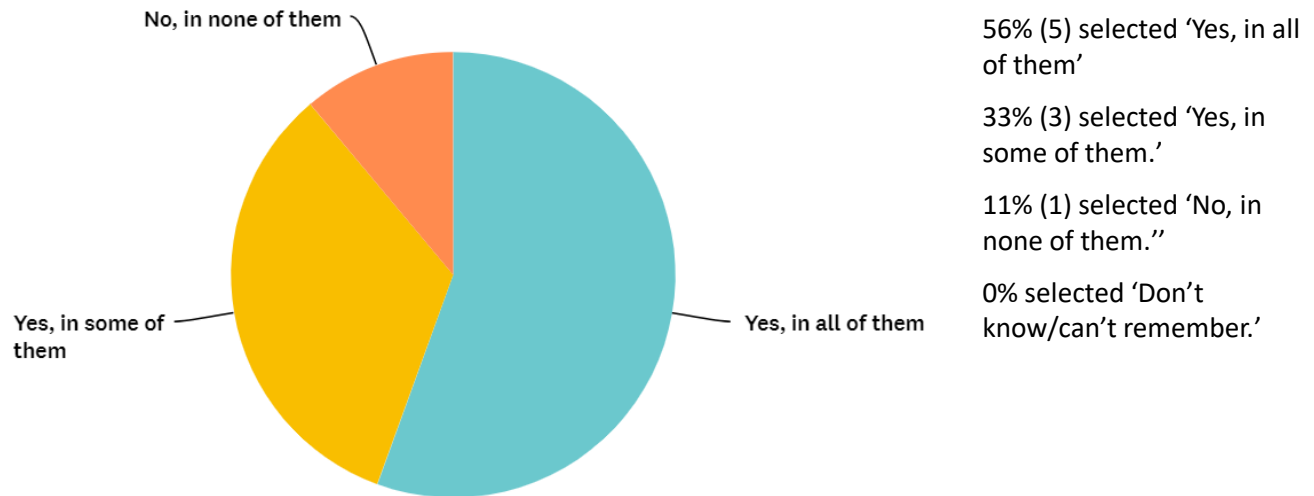
“ I received lots of Macmillan cancer leaflets. I felt overwhelmed by the abundance of paperwork produced by them. I think there were groups mentioned in those leaflets, but I eventually found a comprehensive list of support groups from Breast Cancer Care organisation. But I was grateful for some of the signposting from the Macmillan Online services.”

Comparison with partner/family member/friend's answers (3 respondents)

100% (3) of respondents said their partner/family member/friend was given information about support groups

7.6 CONFIDENCE AND TRUST IN DOCTORS (9 respondents)

Participants were asked: 'Do you/did you have confidence and trust in the doctors treating you?'



One person felt that some ‘[unthinking comments had been made](#)’ by their doctor. Another respondent experienced some challenges that affected their level of trust:

“ The oncologist described the surgeons as the 'heroes' of cancer care, and I initially agreed as tumour removal with clear margins was achieved. But there was very little surgical follow up and I was left to manage wound care and surgical healing alone, or through my GP / GP nurse. This was insufficient as I was eventually referred back to hospital for seroma draining. There was not enough time allotted during oncology appointments to really answer any queries I had. There was a huge error made on my hospital letters where the size and grade was incorrect. I was later informed that this was due to 'Outsourcing letters'. I understood that doctors are under considerable pressure, with large patient lists and complex clinical issues to deal with, but my trust was affected by the error and the lack of appointment follow up.”

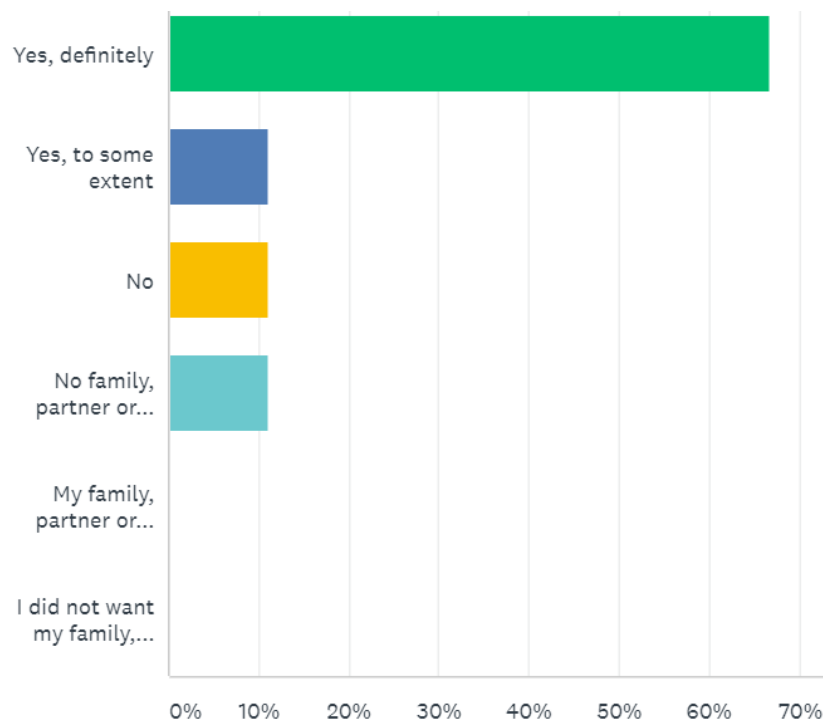
Comparison with partner/family member/friend's answers (3 respondents)

100% (3) of respondents selected ‘Yes, in some of them’

One person commented “Her GP was reluctant to prescribe morphine despite stage 4 diagnosis!”

7.7 FAMILY AND PARTNERS HAVING ACCESS TO A DOCTOR (9 respondents)

Participants were asked: ‘If your family/partner or someone else close to you wanted to talk to a doctor, were they able to?’



67% (6) selected 'Yes, definitely.'

11% (1) selected 'Yes, to some extent.'

11% (1) selected 'No'

11% (1) selected 'No family, partner or friends were involved.'

0% selected 'My family, partner or friends did not want to talk to a doctor' or 'I did not want my family, partner or friends to talk to a doctor.'

One participant reported that 'Nurses were available to talk to my family and friends, but not doctors.' Another respondent commented on how helpful their partner had been in communication with doctors:

“ I was lucky that my partner attended every appointment and received the same information as me. It was very helpful as I was often passive and reluctant to advocate for myself in appointments (distracted by treatments) but my partner spoke up for me at those times.”

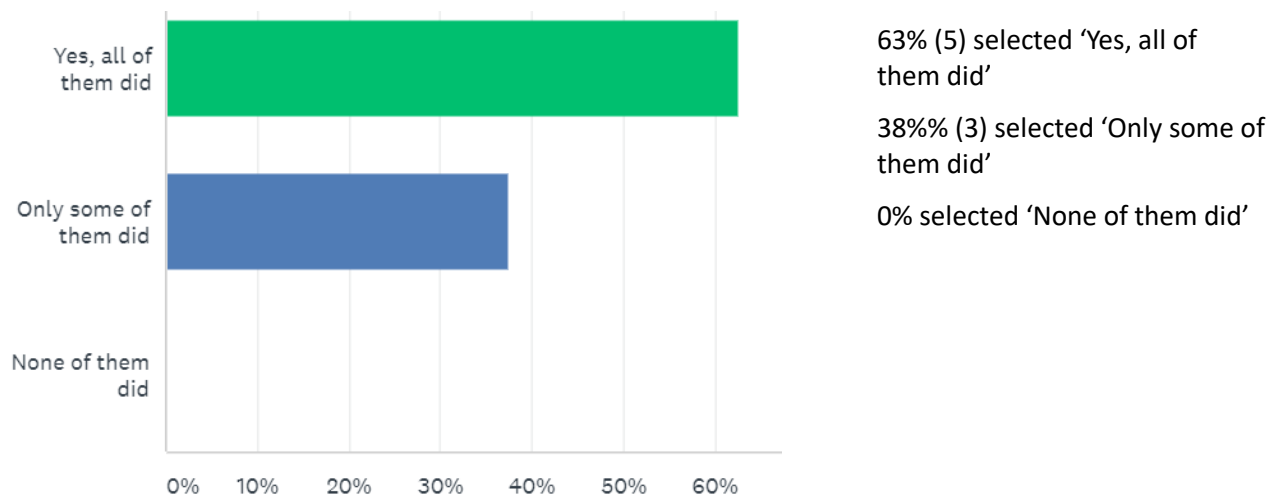
Comparison with partner/family member/friend's answers (3 respondents)

33% (1) of respondents selected 'Yes, definitely'

67% (2) of respondents selected 'Yes, to some extent'

7.8 RESPECT FOR CHOSEN NAME (8 respondents)

Participants were asked: 'Have doctors and nurses asked you what name you prefer to be called by?'



One person noted: “My treatment has all been with my current gender name on all correspondence and paperwork. Never questioned other than whether to be addressed by Christian name or surname.”

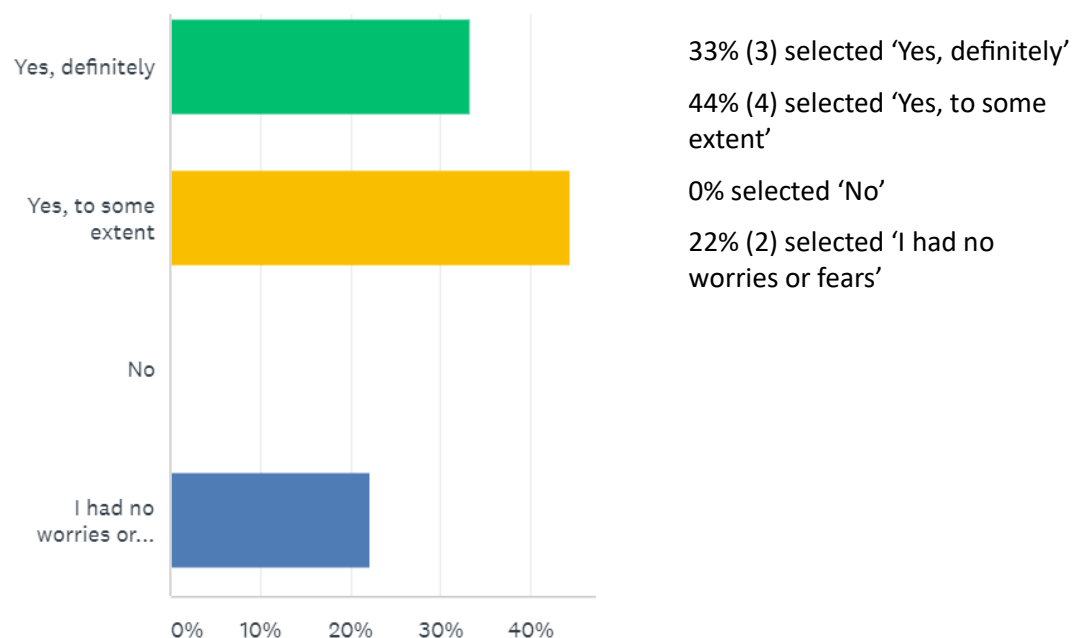
Comparison with partner/family member/friend's answers (3 respondents)

33% (1) of respondents selected ‘Only some of them did’

67% (2) of respondents selected ‘Yes, all of them did’

7.9 BEING ABLE TO DISCUSS WORRIES OR FEARS (9 respondents)

Participants were asked: ‘Have you had healthcare staff to talk to about your worries and fears?’



One person found Macmillan counselling useful:

“ I was thankful to be referred to macmillan Cancer Counselling which proved very helpful. I was asked if i had any preference about the type of counsellor and i didn't. But later I realised I would have preferred a female counsellor. But the male counsellor was empathic and non judgemental.”

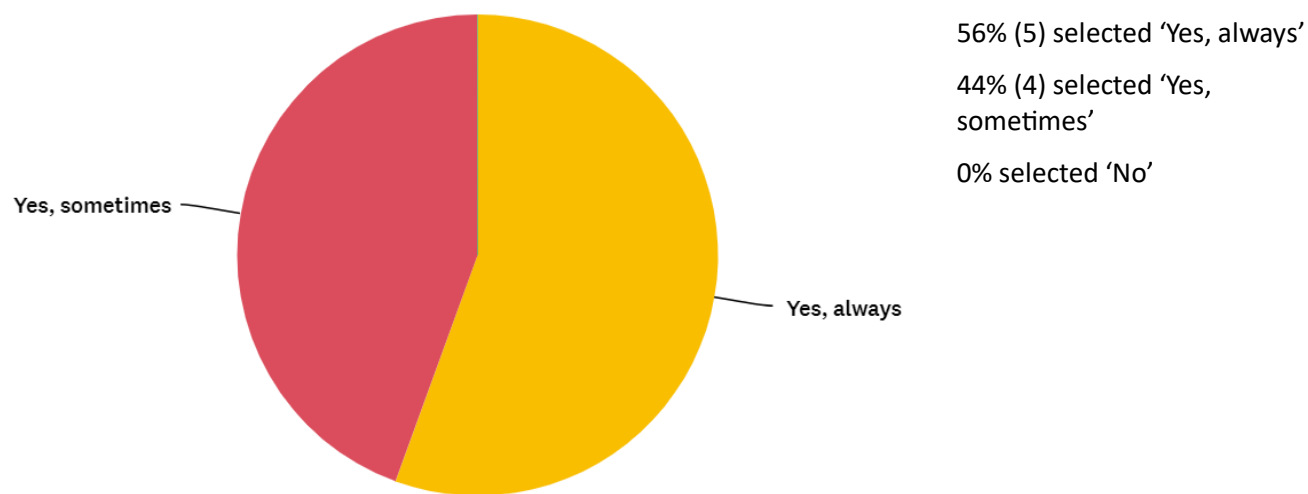
Comparison with partner/family member/friend's answers (3 respondents)

33% (1) of respondents selected 'No'

67% (3) of respondents selected 'Yes, definitely'

7.10 BEING TREATED WITH RESPECT AND DIGNITY (9 respondents)

Participants were asked: 'Overall, do you feel you have been treated with respect and dignity throughout your care?'



Two respondents commented further and had both had variable experiences:

“ Very much down to the individual worker - some incredibly thoughtful and respectful, others extremely patronising.”

“ My experience was variable. The chemotherapy day unit was exceptional with excellent nurses, but the equipment was so lacking that I spent hours with a picc line cap which got stuck and couldn't be removed. I was informed this was due to 'cheaper' caps being supplied by stores. Having visited a London hospital later - it was almost futuristic in it's environment and wide ranging services. There is inequality and lack of standards of care for cancer treatment, and certainly a lack of interest in LGBT background or issues.”

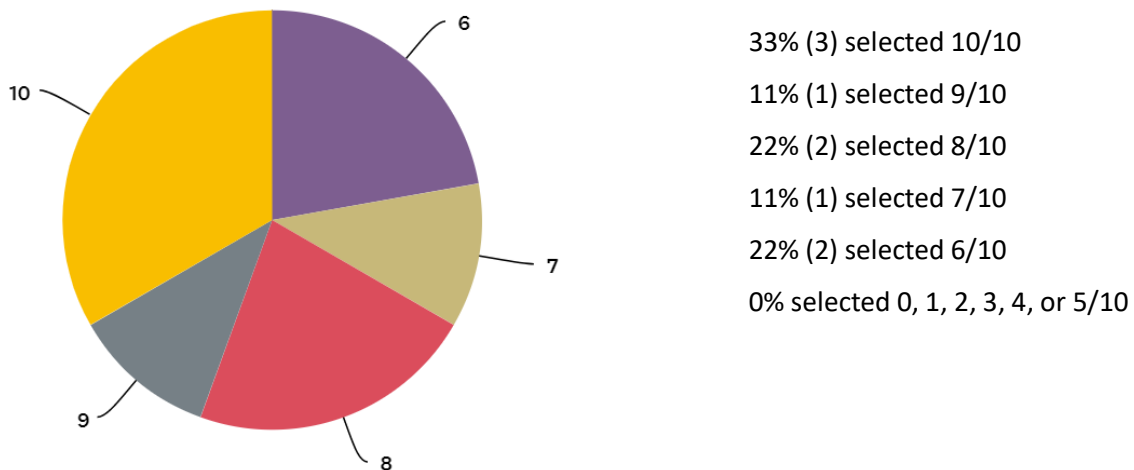
Comparison with partner/family member/friend's answers (3 respondents)

100% (3) of respondents selected 'Yes, always'

7.9 OVERALL RATINGS FOR NHS CARE (9 respondents)

Participants were asked: 'Overall, how would you rate the care you have received from the NHS? 0 = very poor; 10 = very good.'

The average of all scores given was 8.22 out of 10.



Three comments were received about the quality of care respondents had experienced:

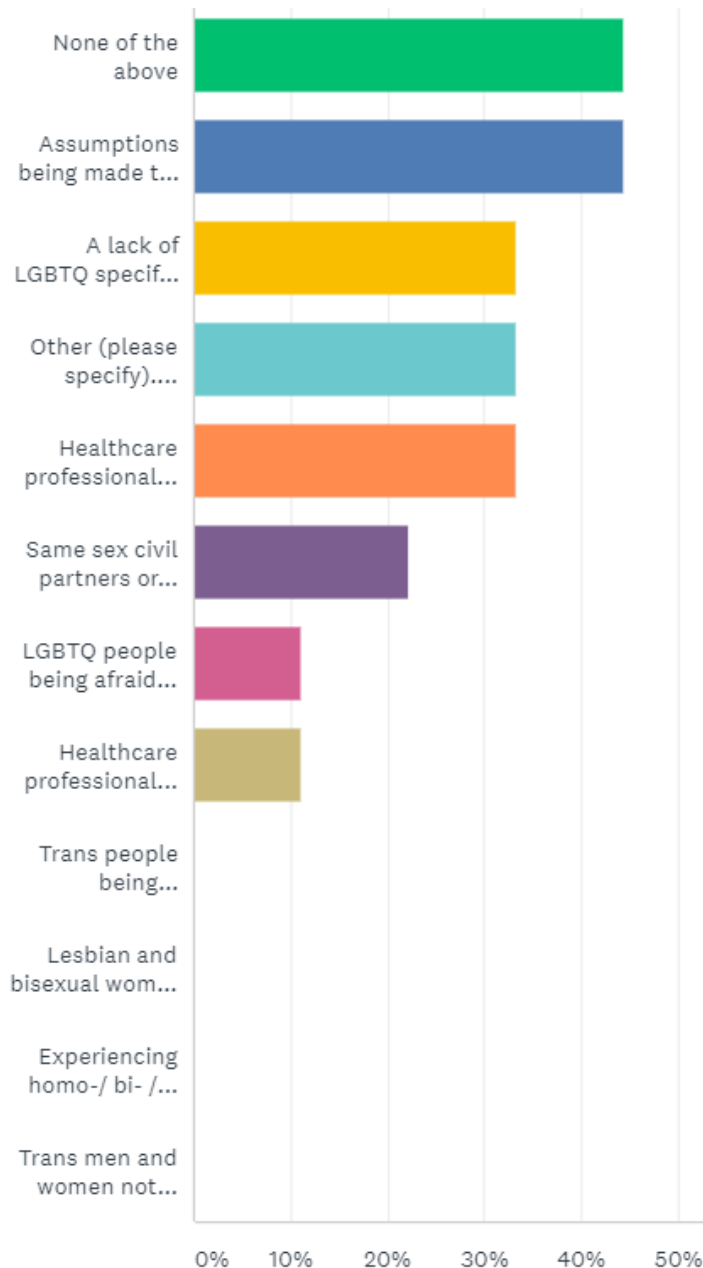
- “ At the end of treatment (surgery) I felt a bit like I'd come through a treatment machine and been dumped when finished. Nobody to talk to without visiting GP till check up 6 months later, though I used Macmillan for phone contact.”
- “ There were different rates of care depending on which department I was dealing with and which pathway of care I was on. I felt that care and attention to LGBT details etc would have been improved if the Trust had better resources, funding and innovation.”
- “ I had a very bad infection after my lumpectomy (eventually requiring a further operation) and it escalated because my cancer nurse sent me to my GP and my GP practice nurse failed to treat it properly. I had an open infected wound and was largely left to my partner to deal with until it got out of control.”

Comparison with partner/family member/friend's answers (3 respondents)

The average of all scores given was 9.33 out of 10.

7.10 BARRIERS TO CANCER TREATMENT, SUPPORT AND/OR CARE (9 respondents)

Participants were asked: 'Have you experienced any of the following barriers in accessing cancer treatment, support and/or information? Please select all that apply.'



44% (4) selected 'Yes, definitely.'

44% (4) selected 'Assumptions being made that all patients are heterosexual and cisgendered (i.e. people whose experiences of their own gender agree with the sex they were assigned at birth).'

33% (3) selected 'A lack of LGBTQ specific information and resources e.g. posters, leaflets'

33% (3) selected 'Other (please specify). Please tell us about any/all of the barriers you have experienced.'

33% (3) selected 'Healthcare professionals not being LGBTQ-aware and inclusive'

22% (2) selected 'Same sex civil partners or spouses not being recognised as next of kin'

11% (1) selected 'LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia'

0% selected:

- 'Trans people being mis-gendered by professionals'
- 'Lesbian and bisexual women being told they don't need to have cervical screening'
- 'Experiencing homo-/ bi- / transphobia from professionals,' or
- 'Trans men and women not receiving relevant information about the need for cervical screening and prostate screening'

Three people selected 'Other (please specify). Please tell us about any/all of the barriers you have experienced.' Their comments are below:

“ Embarrassment at pharmacy counter when prescriptions were titled in my previous gender and name. Assistant calling out my old name and title to those waiting when it is my turn to collect from counter.”

“ These problems more likely from other patients!”

“ All my poor experiences were in Hayward’s Heath Princess Royal - Brighton cancer staff full inclusive and aware. Also Breast Cancer care charity materials given to us for my partner are heterosexist - I wrote to them about this and didn’t receive a reply.”

Comparison with partner/family member/friend's answers (3 respondents)

33% (1) selected ‘A lack of LGBTQ specific information and resources e.g. posters, leaflets’

33% (1) selected ‘Assumptions being made that all patients are heterosexual and cisgendered’

33% (1) selected ‘Same sex civil partners or spouses not being recognised as next of kin’

33% (1) selected ‘LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia’

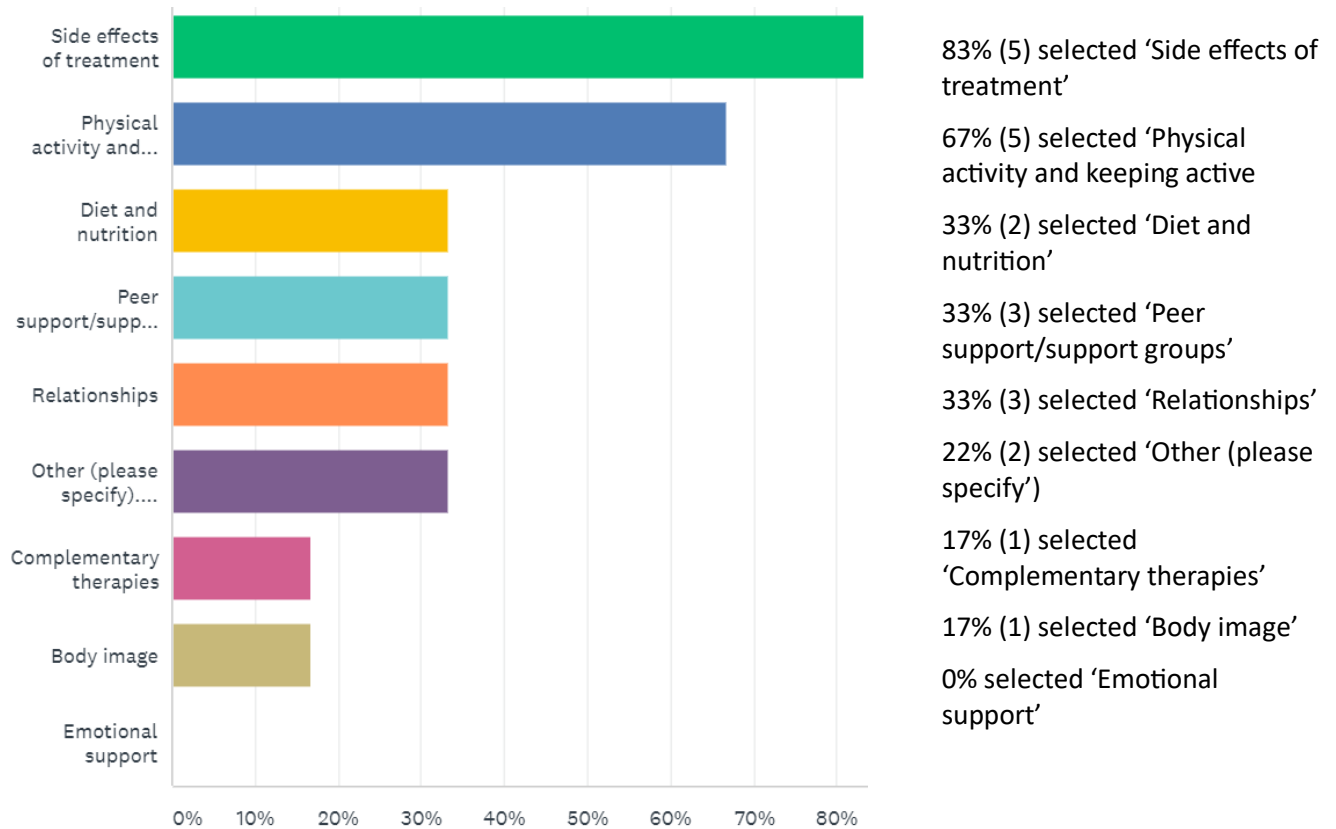
33% (1) selected ‘Lesbian and bisexual women being told they don't need to have cervical screening’

33% (1) selected ‘Healthcare professionals not being confident to discuss sexual health issues with LGBTQ people’

33% (1) selected ‘None of the above’

7.11 GAPS IN INFORMATION OR SUPPORT (6 respondents)

Participants were asked: ‘*Is there any information or support you felt you needed at any point but did not have? Please select any that apply.*’

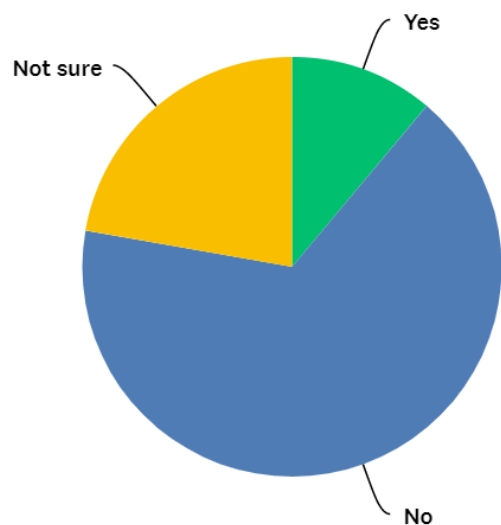


Two people left comments. One person said “A good deal of 'advice' given, which sometimes felt quite punitive, that I was doing it wrong.” Another commented on variance between facilities:

“ I have accessed the Horizon Macmillan Centre in Brighton which was lovely. But apart from counselling/mindfulness referral, there was very little 'in-house' options for support at my local hospital in Eastbourne.”

7.12 BARRIERS RELATING TO SEXUALITY OR GENDER (9 respondents)

Participants were asked: ‘Have you experienced any barriers or challenges in accessing information, support or treatment relating to your sexuality or gender?’



67% (6) selected 'No'
22% (2) selected 'Not sure'
11% (1) selected 'Yes'

Two comments were received:

- “ Just the main issue - assumption of my heterosexuality right from the start. Because of feeling low, lacking confidence, I couldn't find the words to challenge this assumption!”
- “ I just wish that in the mountains of leaflets and the throughout the various appointments within surgery, chemo and radiotherapy - there would have been a space for inclusive support for LGBT people.”

8. KEY FINDINGS

This section overviews some of the key areas of information gathered during the research.

8.1 COMPARISON OF SURVEY DATA WITH NHS ENGLAND'S CANCER PATIENT EXPERIENCE SURVEY 2016 NATIONAL REPORT

Some of the questions in our survey for LGBTQ people affected by cancer were drawn from NHS England's Cancer Patient Experience Surveys (CPES). Below is a comparison with some of the findings in the 2016 National Report, which does not present filtered results for sexual orientation or trans status. The questions presented below are those from our research that are taken directly from the CPES questions.

It should be noted that most of these questions were responded to by a relatively low number of LGBTQ participants affected by cancer – around 9. Our survey found that our Brighton, Hove and Sussex-based LGBTQ respondents had less positive experiences than their counterparts in the 2016 CPES; often significantly less positive.

Survey item	CPES 2016 – all respondents	Brighton, Hove and Sussex-based LGBTQ respondents
Percentage of respondents who said that the amount of time they had to wait for their (last) test to be done was about right.	87%	78%
Percentage of respondents who said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment.	90%	67%
Percentage of respondents who said they were given information about support or self-help groups for people with cancer.	84%	56%
Percentage of respondents who said that they had confidence and trust in all of the doctors treating them	85%	56%
Percentage of respondents who said that, if their family or someone else close to them wanted to talk to a doctor, they were definitely able to	73%	67%
Percentage of respondents who said that, while they were in hospital, all of the doctors and nurses asked them what name they prefer to be called by.	68%	63%
Percentage of respondents who said that, overall, they were always treated with respect and dignity while they were in hospital. [our survey question was 'overall, throughout your care' rather than 'in hospital']	88%	56%
Overall rating of their care on a scale of zero (very poor) to 10 (very good)	8.74	8.22

8.2 KEY SURVEY FINDINGS REGARDING BARRIERS TO CANCER TREATMENT, SUPPORT AND/OR CARE:

Below is a table comparing professional’s responses to the question about barriers with LGBTQ community members’ responses. Professionals and LGBTQ people affected by cancer have similar response rates to some of the barriers but LGBTQ people affected by cancer experience a lack of LGBTQ specific information and resources e.g. posters, leaflets as a barrier than professionals thought it would be.

LGBTQ people affected by cancer were asked ‘Have you experienced any of the following barriers in accessing cancer treatment, support and/or information? Please select all that apply.’

Professionals supporting people with cancer were asked ‘In your experience, what (if any) barriers do LGBTQ people experience in accessing cancer treatment, support and/or information? Please select all that apply.’

Survey item	LGBTQ people affected by cancer	Professionals supporting people with cancer
A lack of LGBTQ specific information and resources e.g. posters, leaflets	33%	24%
Assumptions being made that all patients are heterosexual and cisgendered	44%	45%
Healthcare professionals not being LGBTQ-aware and inclusive	33%	35%
Experiencing homo-/ bi- / transphobia from professionals	-	10%
Same sex civil partners or spouses not being recognised as next of kin	22%	14%
Trans people being misgendered by professionals	-	21%
Trans men and women not receiving relevant information about the need for cervical screening and prostate screening	-	21%
LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia	11%	17%
Lesbian and bisexual women being told they don't need to have cervical screening	-	17%
Healthcare professionals not being confident to discuss sexual health issues with LGBTQ people	11%	21%
None of the above	44%	17%
Other (please specify)*	33%	17%

* Other barriers identified by LGBTQ people affected by cancer:

- Being misgendered and an old name/title being used at a pharmacy
- Potential problems from other patients
- Heterosexist breast cancer information
- Staff at Hayward's Heath Princess Royal being less LGBTQ-inclusive and aware

* Other barriers identified by professionals:

- Partners not being recognised as Next of Kin, including concerns for partners of people not in legally-recognised relationships.

8.3 QUALITATIVE DATA: BARRIERS IDENTIFIED WITHIN INTERVIEWS AND FOCUS GROUPS WITH LGBTQ PEOPLE AFFECTED BY CANCER AND WITH PROFESSIONALS SUPPORTING PEOPLE WITH CANCER

Several themes emerged regarding inequalities in cancer care, information and support experienced by LGBTQ people affected by cancer. They are as follows:

Next of Kin

- An interviewee was asked who her next of kin was at The Princess Royal, and when she gave her female partner's name this was queried, which the interviewee said made her 'very cross' as she did not believe this would have happened if she gave a male partner's name.
- A healthcare professional gave the example of lesbians who were not out being asked "Is your husband coming in?" rather than 'partner,' and of lesbians being written to as 'Mrs.'
- Two interviewees described the frustration at being asked repeatedly to take pregnancy tests, even when, in one person's case, she hadn't had sex with a man for over 25 years.
- An example was given by a cancer professional of a 45-year-old lesbian being told by her GP that she had an ovarian cyst, and the GP wanting to 'bring her husband in' to disclose the bad news. When she told the GP that she had a female partner he said that she did not need anyone there after all and told her there and then that she needed to have a hysterectomy.

Accessing relevant education and health promotion information

- An interviewee wrote to the Breast Cancer Care charity with feedback that she and her partner found the resource pack very heterocentric; she did not receive a reply.
- Most existing cancer literature and information is geared towards a heterosexual, cisgender audience, with very low visibility of LGBTQ couples and individuals. LGBTQ people may feel the information is not relevant to them.

Coming out and monitoring

- A few participants commented on the assumption being made that they were all heterosexual, placing the onus on them to self-disclose if they wanted to be 'out' regarding their sexual orientation.
- A gay male interviewee observed that older gay men in particular might feel uncomfortable with coming out.
- A cancer professional felt that routinely monitoring patients' sexual orientation, gender identity and trans status could really improve patient experience throughout services and systems and could help LGBTQ patients feel more 'cared for' by the Trust.

- The widespread lack of monitoring makes it difficult for staff to be aware of individual LGBTQ people's needs.
- LGBTQ people may be concerned, perhaps based on past experiences, that their identities may hinder access to services and support.
- A few experiences described suggest that cancer services would be improved if LGBTQ people affected by cancer didn't have to continuously 'come out' to their professionals and then manage those professionals' responses.
- Some professionals supporting people affected by cancer felt that understanding someone's sexual orientation, gender identity and/or trans status is not important in providing them the best possible cancer care. Some professionals have also said they feel it is not important to monitor LGBTQ identities as 'people will tell us if it's important to them.'
- However, other professionals and some LGBTQ people affected by cancer have highlighted the need for monitoring as a way to encourage LGBTQ people to feel safe in 'coming out' about their identities, and thus receiving the most relevant information available to them and having their needs met more fully.

Heteronormativity

- Some LGBTQ people feel it is incumbent on them to educate their healthcare professionals about their identities, needs and preferences but this self-advocacy is time-consuming, tiring and uses much-needed energy when people are already unwell.
- One bisexual interviewee said that a number of times assumptions were made that she was heterosexual as she had a male partner, and that 'little things like that make you feel overlooked.'

Support networks

- Two LGBTQ people affected by cancer and one professional highlighted the value of a supportive network during/after cancer treatment and noted that some LGBTQ people might face more challenges as they may be estranged from their families due to homo-/ bi-/ transphobia.

Experiences of trans people affected by cancer

- A few interviewees described the experiences of transgender people attending screenings with people of the opposite gender and finding this distressing, e.g. trans women attending prostate cancer screenings with men, or trans men attending cervical screenings with women.
- A number of interviewees felt that while it was particularly important to be aware of trans people's needs in order to give them the right screening information, transgender people often do not receive adequate information about the need for cervical and prostate screening.
- A cancer professional noted that research shows trans people are less likely to access treatment due to the fear of negative outcomes if they disclose their trans status.
- A professional felt that some trans people might be put off accessing cancer screening for the opposite gender, particularly as most screening information doesn't focus on the needs of trans people.

- The same professional described the experience of a trans man with vaginal cancer for whom the focus on his vagina was deeply distressing; she noted that treating him may also have been uncomfortable for his healthcare professionals.
- Another example was given by a professional of a trans woman with prostate cancer who felt that her gender identity was totally sabotaged by her cancer treatment, with untold negative consequences for her mental and emotional health.

Cervical screening for lesbians

- Several participants commented on the experiences of lesbians being told by GPs that they don't need cervical screening and are at lower risk/no risk of cancer. One of our focus group members said she had been told that if her partner's cervical cancer been diagnosed one month sooner (their GP said that screening was unnecessary as she didn't have children, wasn't having penis-in-vagina sex and not taking a contraceptive pill), she would still be alive today.
- Other interviewees felt that some lesbians have had negative experiences of cervical screening, especially if they're not used to penis-and-vagina sex.
- Cervical cancer is one of the most treatable cancers if an early intervention is received, so these barriers can have profound consequences.

Diagnosis

- A cancer professional felt the greatest barriers for LGBTQ patients are primarily diagnostic; many LGBTQ patients may not disclose potential cancer signs to their GPs because of their fear of discrimination, and that if they don't have a good relationship with their GP they may not feel welcomed or heard.

Mental health

- One professional described the experience of a gay man whose cancer diagnosis (experienced as traumatic) triggered his bipolar disorder but his cancer was treated without acknowledging the impact this was having on his mental health.
- The same professional felt that the impact of homo-/bi-/transphobia can prevent some LGBTQ people from accessing mental health treatment.

Sexual health

- A gay male interviewee felt some gay men might be uncomfortable discussing their sexual health because assumptions might be made about them, e.g. that all gay men enjoy anal sex.
- A cancer professional gave a hypothetical example of a gay man presenting at A&E with rectal bleeding, which can be a symptom of cancer, but might be read as the result instead of anal sex, which could lead to less compassionate treatment.
- Because of the impact of cancer and its treatment for some people on sexual function and relationships, it's important for cancer professionals to understand people's sexual orientations and gender experiences in order to offer appropriate and relevant support and be comfortable discussing their sexual relationships and behaviours.
- A couple of LGBTQ people affected by cancer felt that healthcare professionals had been uncomfortable discussing sexual relationships with them. A professional echoed that 'private parts' are uncomfortable for some professionals to discuss.

- A professional felt that older people in the LGBTQ community may be more hesitant to discuss their LGBTQ identities, or sensitive issues including, for example, erectile dysfunction.

Homo-/bi-/transphobia and their impact

- A professional with an LGBTQ identity felt that queer people may have become used to humiliation and may feel that they can't 'make a fuss' - perhaps coming to accept that their own needs might not be met.
- The same professional witnessed gay men in a cancer treatment setting being seen as 'fun' and objects of humour who were gently ridiculed in relation to their sexual orientation.
- Another professional noted that most LGBTQ people have already experienced some trauma in their lives in terms of coming out and experiencing homo/bi/transphobia. In her opinion, this trauma can delay or prevent LGBTQ people from accessing treatment for their mental health.
- An interviewee felt that LGBTQ people experiencing cancer have a 'double whammy' in terms of their illness and the additional impact of 'LGBTQ abuse.'

9. CONCLUSIONS

Our survey data (albeit with a relatively small sample size) shows that the LGBTQ people affected by cancer that we engaged with, experienced a number of inequalities in terms of some aspects of the care, support and resources they have received.

Participants in this research have identified several barriers that prevent LGBTQ people affected by cancer from accessing cancer treatment, support and/or information.

A clear need has been identified by LGBTQ people affected by cancer and professionals for widespread LGBTQ-awareness training to be co-produced with people with relevant lived experience and delivered to all healthcare professionals working with people with cancer.

10. RECOMMENDATIONS

These recommendations have been developed out of the findings of the online surveys, interviews and focus groups. It is hoped that the following recommendations may act as a guide for cancer healthcare providers and general practice.

General recommendations:

1. All healthcare professionals, including district nurses, hospital staff and those working in community settings, should receive training about LGBTQ-inclusive practice and trans awareness.
2. Service providers to survey their staff to identify priority areas for relevant training, e.g. LGB awareness, trans awareness, understanding the specific needs of LGBTQ people affected by cancer.
3. All such training should co-produced with LGBTQ people affected by cancer and should be a combined professional-community effort.
4. Cancer healthcare providers should deliver outreach to LGBTQ communities in general healthcare settings. This should include raising awareness of cancer signs, symptoms and screening – online, in GP surgeries, sexual health clinics and more. LGBTQ-inclusive posters and leaflets would work well in GP waiting rooms and improve access to cancer information for LGBTQ patients.

5. Cancer healthcare providers should use cancer-related education opportunities in LGBTQ community settings e.g. drop-ins at community bars/pubs, and a stall at Brighton Pride.
6. Cancer healthcare providers should make specific efforts to produce and distribute information for GP's regarding the importance of encouraging cervical screening for lesbians and offering trans-specific screening information and encouragement.
7. Cancer healthcare providers should consider developing LGBTQ champions in each department or community setting. They can champion LGBTQ rights and deal with any specific areas within their remit, e.g. encouraging complaints at A & E to identify and respond to issues, and feed learning back to staff after action reviews.
8. Cancer healthcare providers should provide and make accessible clear information about complaints processes.
9. Cancer services should have an LGBTQ-inclusive statement on display - but only if supported by staff training in LGBTQ awareness and inclusion.
10. Cancer healthcare professionals who are LGBTQ and feel comfortable to openly disclose their identities in some way, should do so to help LGBTQ patients feel safer to disclose their own identities.
11. Monitoring patients' sexual orientation, gender identity and trans status should be adopted as standard at every stage of people's cancer pathways to support understanding and responding to the particular needs of LGBTQ people affected by cancer and encouraging them to feel safer to discuss their own needs and concerns.
12. Mental health advocacy might be useful for some LGBTQ people in their meetings with cancer clinicians because if their mental health worsens they may be unable to adhere to their treatment plans with worse outcomes all round.
13. Clinical Nurse Specialists should consider sending out questions to LGBTQ patients the week before their meetings so that the conversations could really focus on their particular needs, and they could openly discuss any potentially difficult issues, such as sexual health, that had been raised in writing.

Recommendations for Macmillan

1. Macmillan should develop LGBTQ peer support groups in partnership with LGBTQ people affected by cancer.
2. Macmillan Cancer Support and other cancer information/support/treatment providers should develop LGBTQ-inclusive literature with representation of LGBTQ people. Resources should be co-produced with LGBTQ people affected by cancer.
3. Macmillan's website should develop an LGBTQ-specific area with relevant information and resources.
4. Macmillan's flagship The Horizon Centre should consider embarking on applying for LGBT Switchboard's 'LGBTQ Inclusion Award', as an example of best practice in LGBTQ affirmative practice and inclusion.

Key Contacts

Daniel Cheesman, LGBT Switchboard CEO:

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Richard Longrigg, Partnership Quality Lead, East Surrey and Sussex, Macmillan Cancer Support:

RLongrigg@macmillan.org.uk

11. APPENDICES

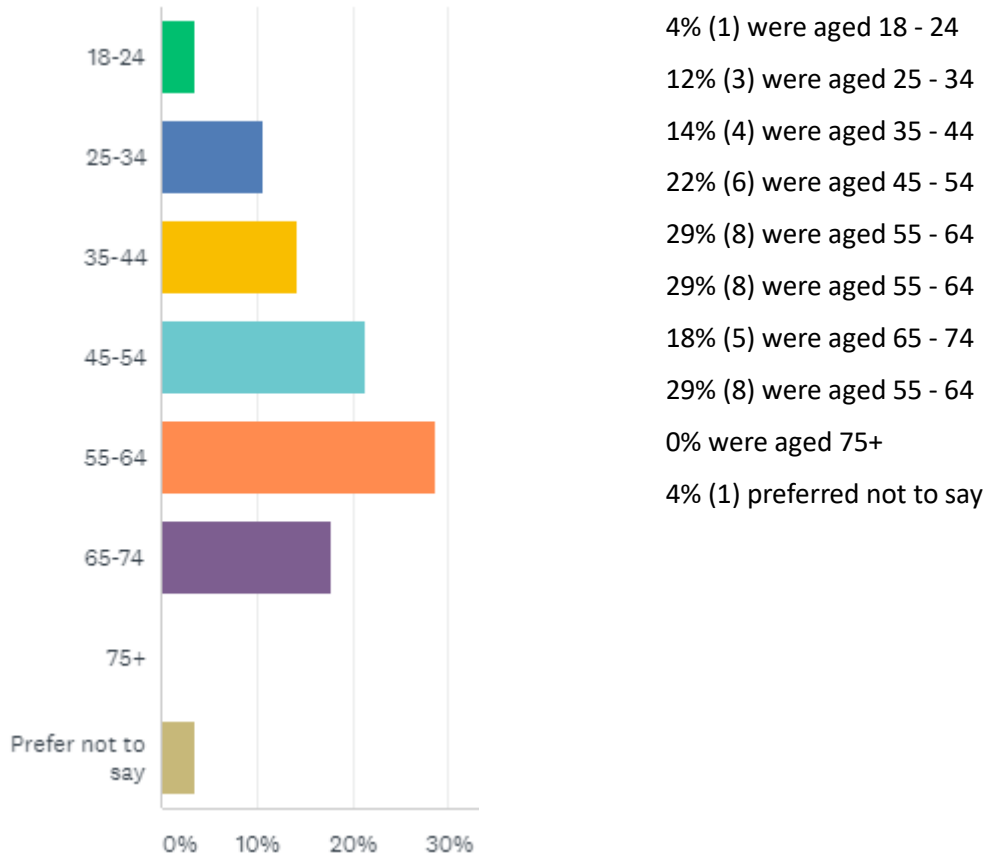
11. 1 DEMOGRAPHIC INFORMATION FROM ONLINE SURVEY: LGBTQ PEOPLE AFFECTED BY CANCER

11.2 DEMOGRAPHIC INFORMATION FROM ONLINE SURVEY: PROFESSIONALS WORKING WITH PEOPLE AFFECTED BY CANCER

Demographic information from online survey: LGBTQ people affected by cancer

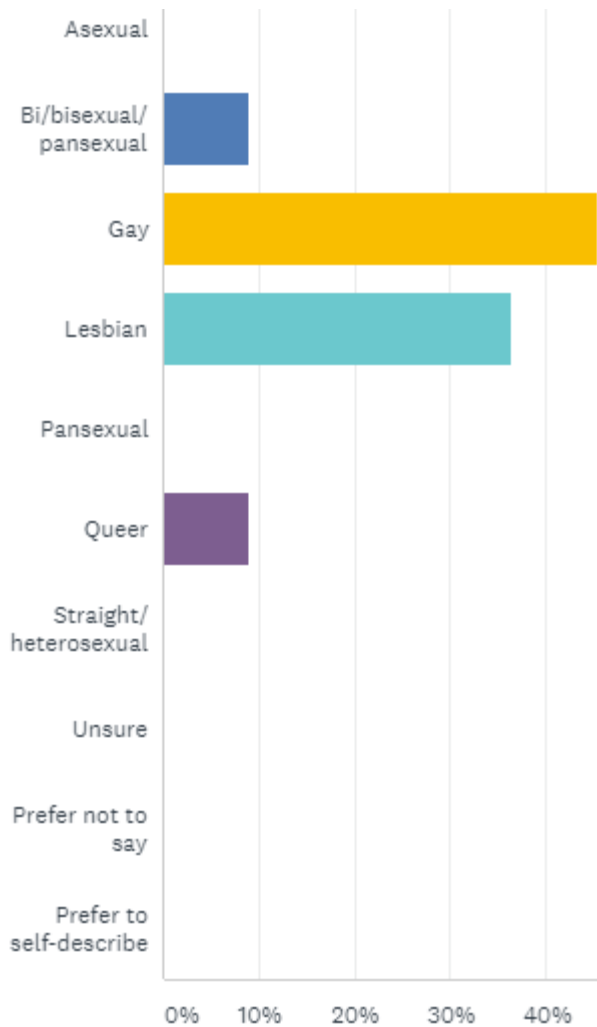
Age (11 respondents)

Participants were asked to select their age from a range of banded options. The age distribution showed the highest proportion of respondents to be between the ages of 45 and 54.



Sexual Orientation (11 respondents)

Participants were asked 'How would you describe your sexual orientation?' and were able to select more than one option.



0% indicated that they identified as asexual

9% (1) indicated that they identified as bisexual

45% (5) indicated that they identified as gay

36% (4) indicated that they identified as a lesbian

0% indicated that they identified as pansexual

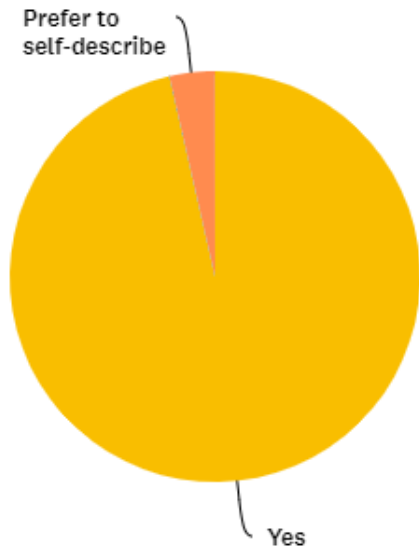
9% (1) indicated that they identified as queer

0% indicated that they were straight/heterosexual

0% indicated that they were unsure or preferred to self-describe

Transgender status (28 respondents)

Participants were asked: 'Does your gender identity match the one you were assigned at birth?'



0% of respondents identified as agender

34% (9) of respondents identified as man

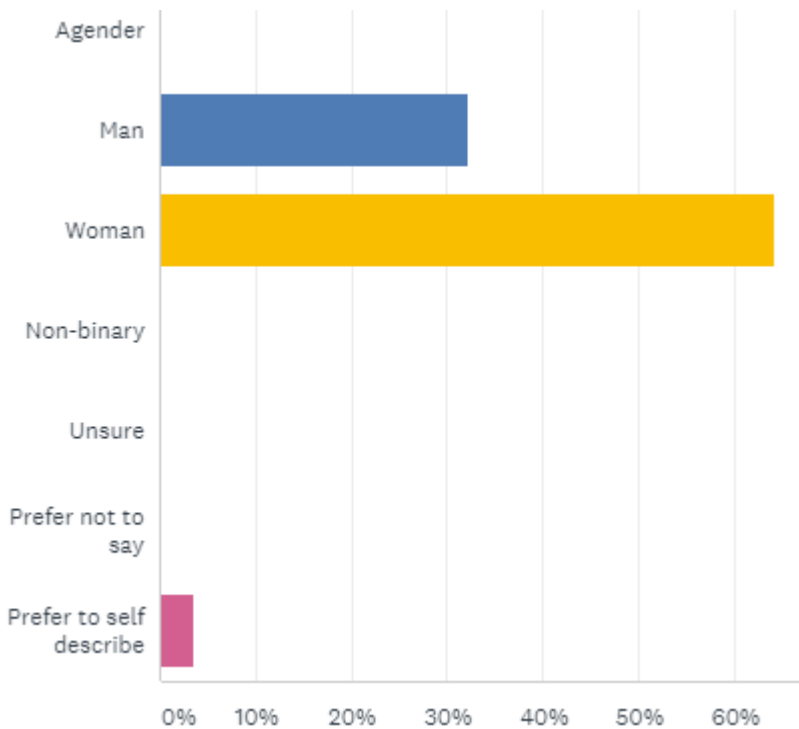
64% (18) of respondents identified as woman

0% of respondents identified as non-binary, unsure or indicated that they preferred not to say

4% (1) preferred to self-describe and gave their identity as 'genderfluid.'

Gender Identity (28 respondents)

Participants were asked to select which of the gender identities from the following list best described them: agender, man, woman, non-binary, unsure, prefer not to say or prefer to self-describe. Respondents could select more than one option.



0% of respondents identified as agender

34% (9) of respondents identified as man

64% (18) of respondents identified as woman

0% of respondents identified as non-binary, unsure or indicated that they preferred not to say

4% (1) preferred to self-describe and gave their identity as 'genderfluid.'

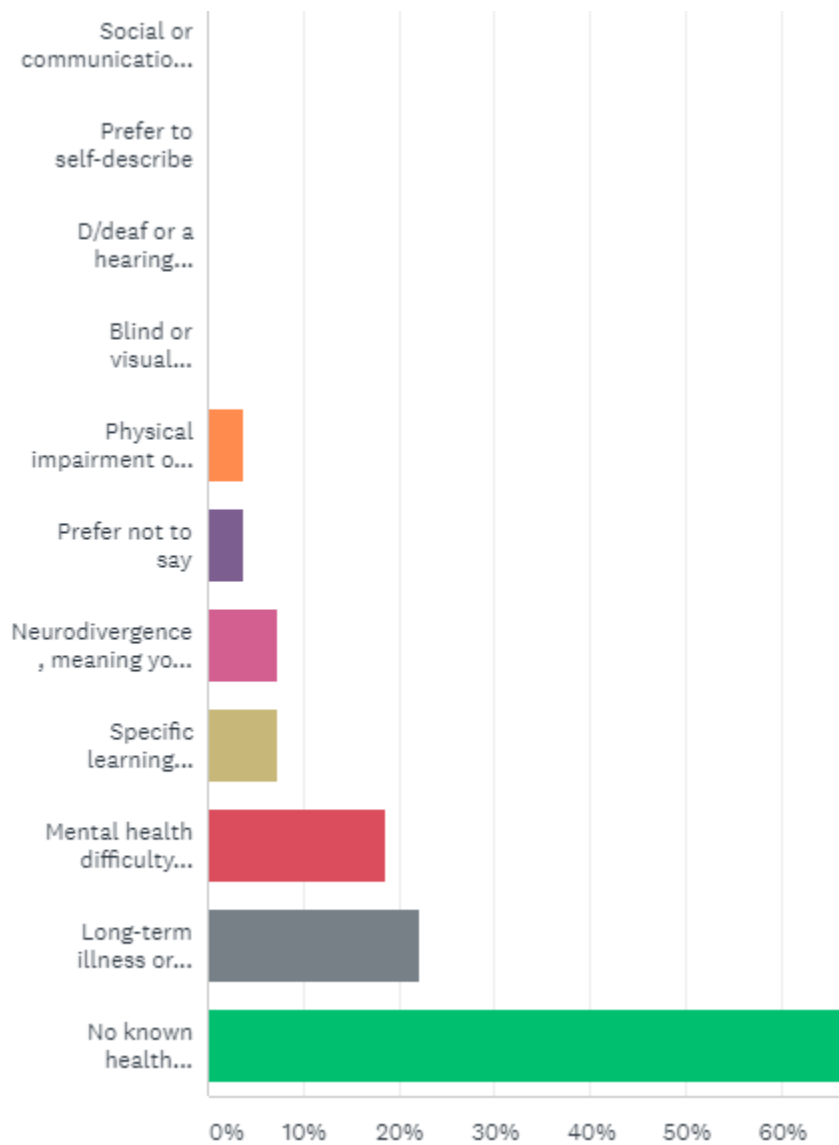
Intersex variation (28 respondents)

Participants were asked: 'Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.'

100% (28) of respondents answered with a 'No.'

Health conditions, impairments, learning differences or neurodivergence (27 respondents)

Participants were asked: 'Do you live with a health condition, impairment, learning difference, or neurodivergence that has a substantial or long term impact on your day to day activities? (Select all that apply).'



0% of respondents selected social or communication condition, D/deaf or a hearing impairment, blind or visual impairment or 'prefer to self-describe.'

4% (1) have a physical impairment or mobility issues (e.g. difficulty using their arms, using a wheelchair)

4% (1) preferred not to say

7% (2) selected Neurodivergence, meaning your brain or mind works very differently from social views of what is 'normal' (e.g. AD(H)D, Asperger's syndrome/ other autistic spectrum condition, bipolar, dyscalculia, dyslexia, dyspraxia, Tourette syndrome)

7% (2) selected Specific learning difficulty such as AD(H)D, dyscalculia, dyslexia, or dyspraxia

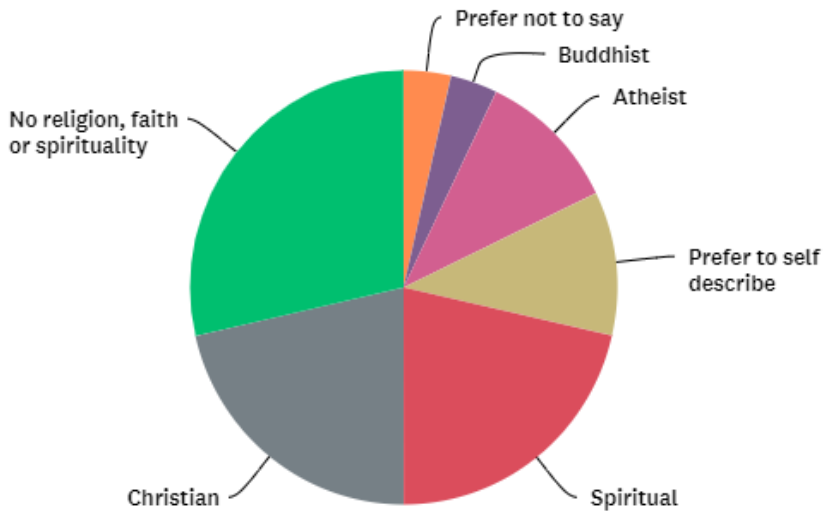
19% (5) have a mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)

22% (6) live with a long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)

67% (18) have no known health condition, impairment, learning difference, or neurodivergence

Religion, faith or spirituality (28 respondents)

Respondents were asked 'If you have a religion, faith, or spirituality, how would you describe it?' The most frequently selected option was 'no religion, faith or spirituality.'



0% of respondents selected Muslim, Hindu, Jewish or Sikh

4% (1) are Buddhist

4% (1) preferred not to say

11% (3) are atheist

11% (3) preferred to self-describe and gave their responses as Quaker, Buddhist Jew and 'no religion'

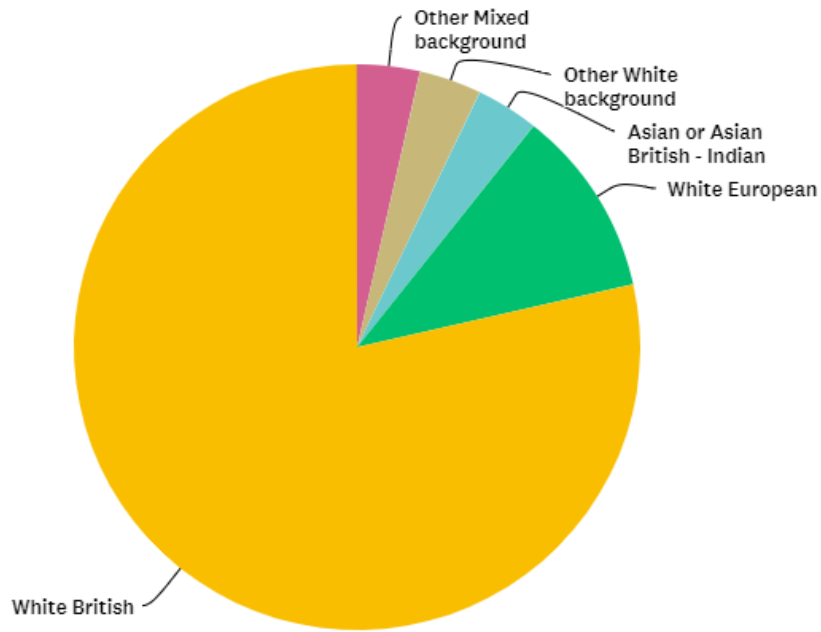
21% (6) selected 'spiritual'

21% (6) are Christian

29% (8) have no religion, faith or spirituality

Ethnic origin (28 respondents)

Respondents were asked to select from a list of terms to describe their ethnic background.



4% (1) selected 'Other mixed background'

4% (1) selected 'Other white background'

4% (1) selected 'Asian or Asian British – Indian'

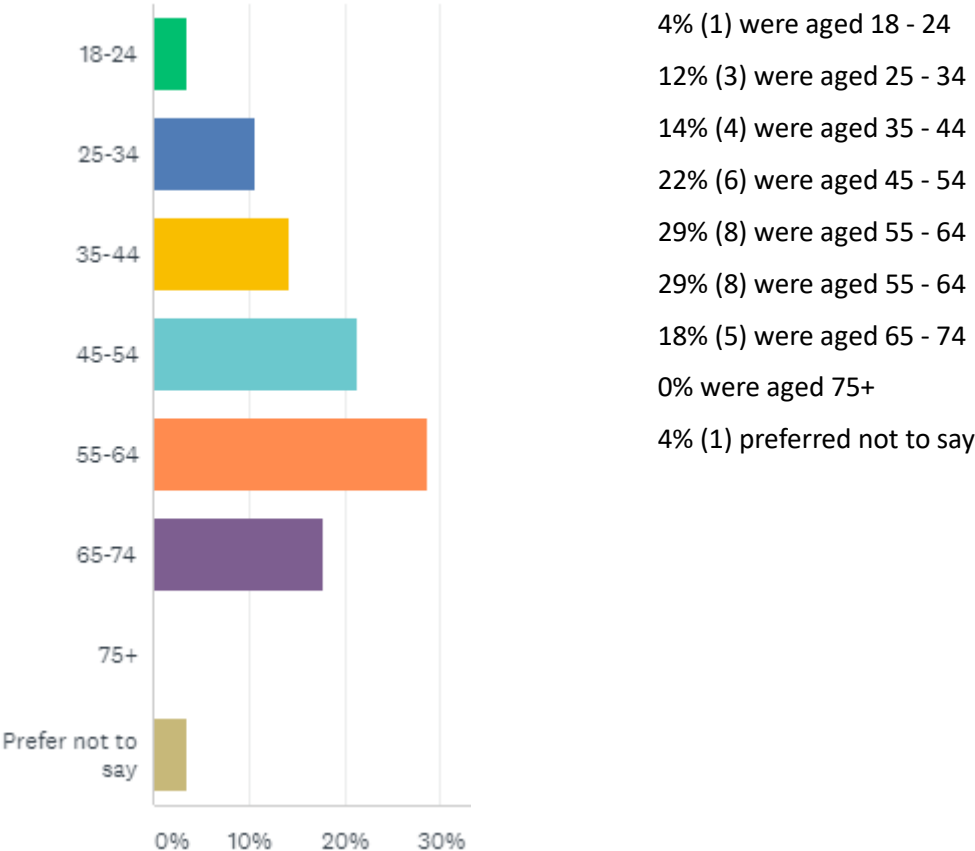
11% (3) selected 'White European'

79% (22) selected 'White British'

Demographic information from online survey: professionals working with people affected by cancer

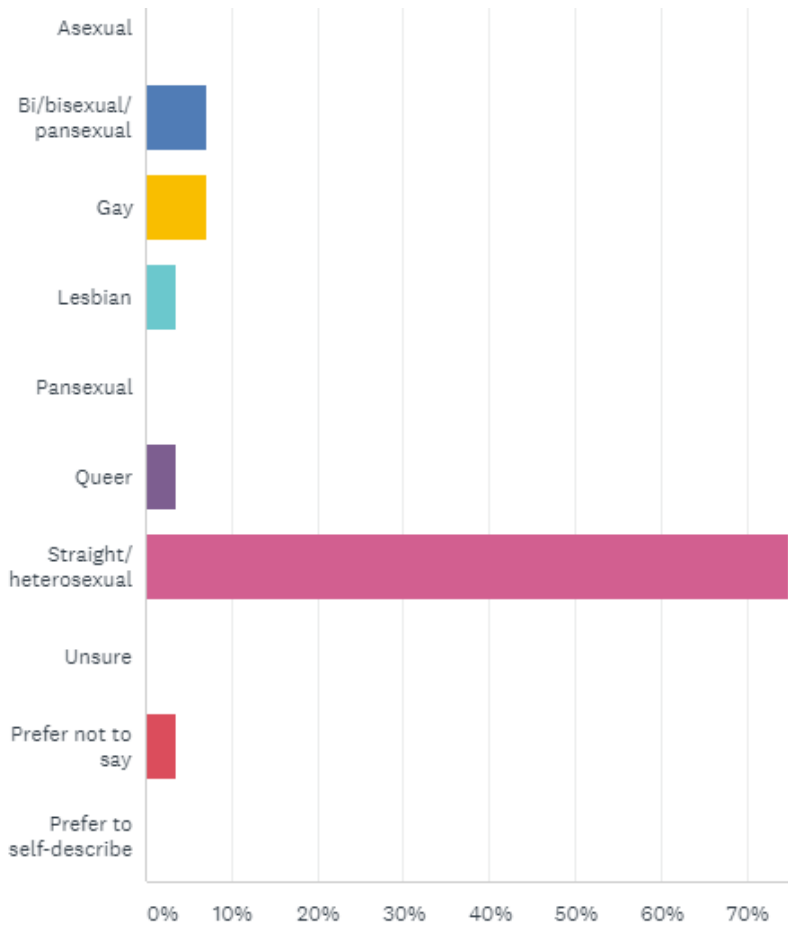
Age (28 respondents)

Participants were asked to select their age from a range of banded options. The age distribution showed the highest proportion of respondents to be between the ages of 55 and 64.



Sexual Orientation (28 respondents)

Participants were asked 'How would you describe your sexual orientation?' and were able to select more than one option.



0% indicated that they identified as asexual

7% (2) indicated that they identified as bisexual

7% (2) indicated that they identified as a gay man

4% (1) indicated that they identified as a lesbian or gay woman

0% indicated that they identified as pansexual

4% (1) indicated that they identified as queer

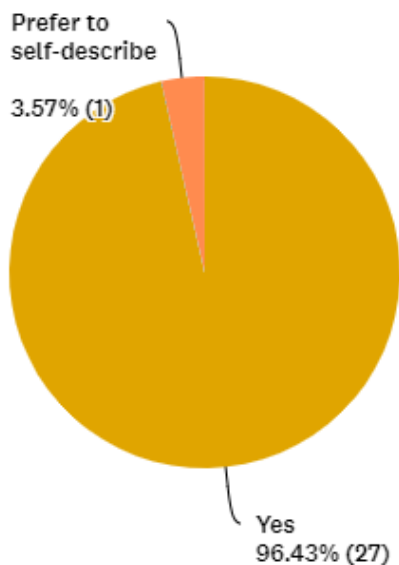
75% (21) indicated that they identified as straight/heterosexual

4% (1) indicated that they preferred not to say

0% indicated that they were unsure or preferred to self-describe

Transgender status (28 respondents)

Participants were asked: 'Does your gender identity match the one you were assigned at birth?'

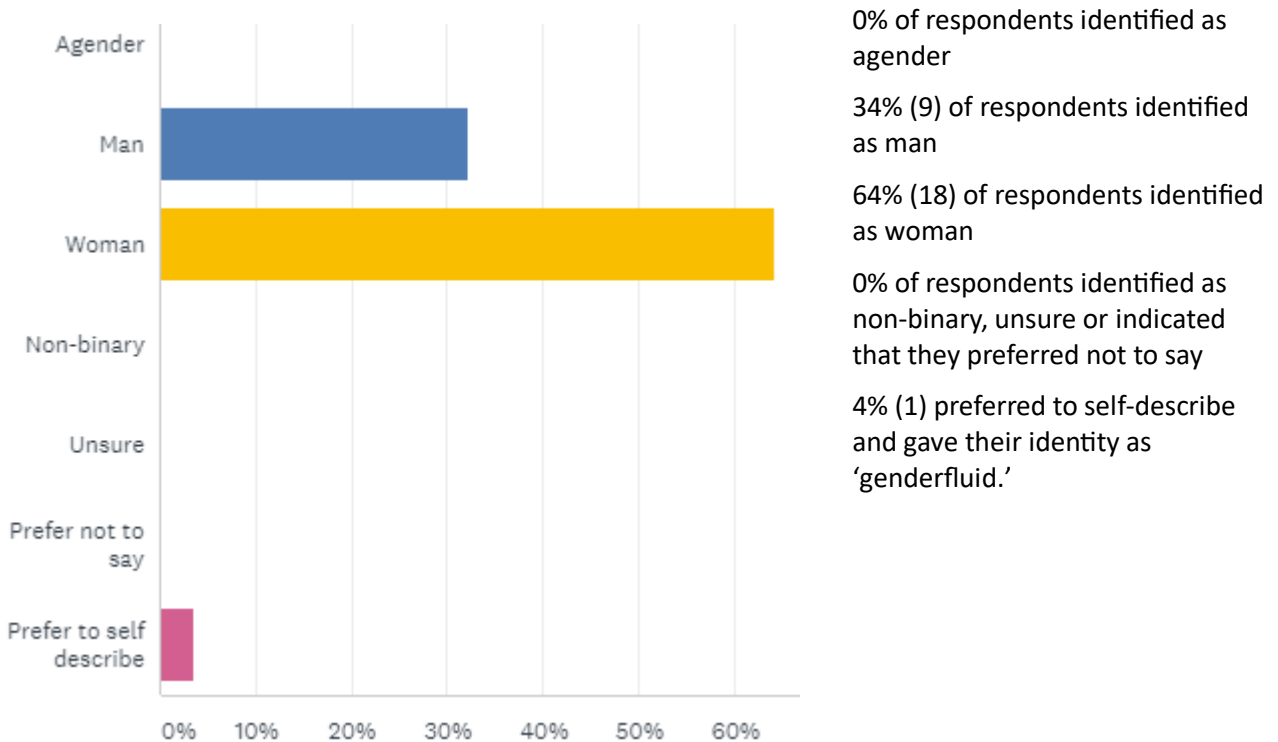


4% (1) of respondents preferred to self-describe, commenting 'Partially but not at all times.'

96% (27) said their gender identity matched the one they were assigned at birth

Gender Identity (28 respondents)

Participants were asked to select which of the gender identities from the following list best described them: agender, man, woman, non-binary, unsure, prefer not to say or prefer to self-describe. Respondents could select more than one option.



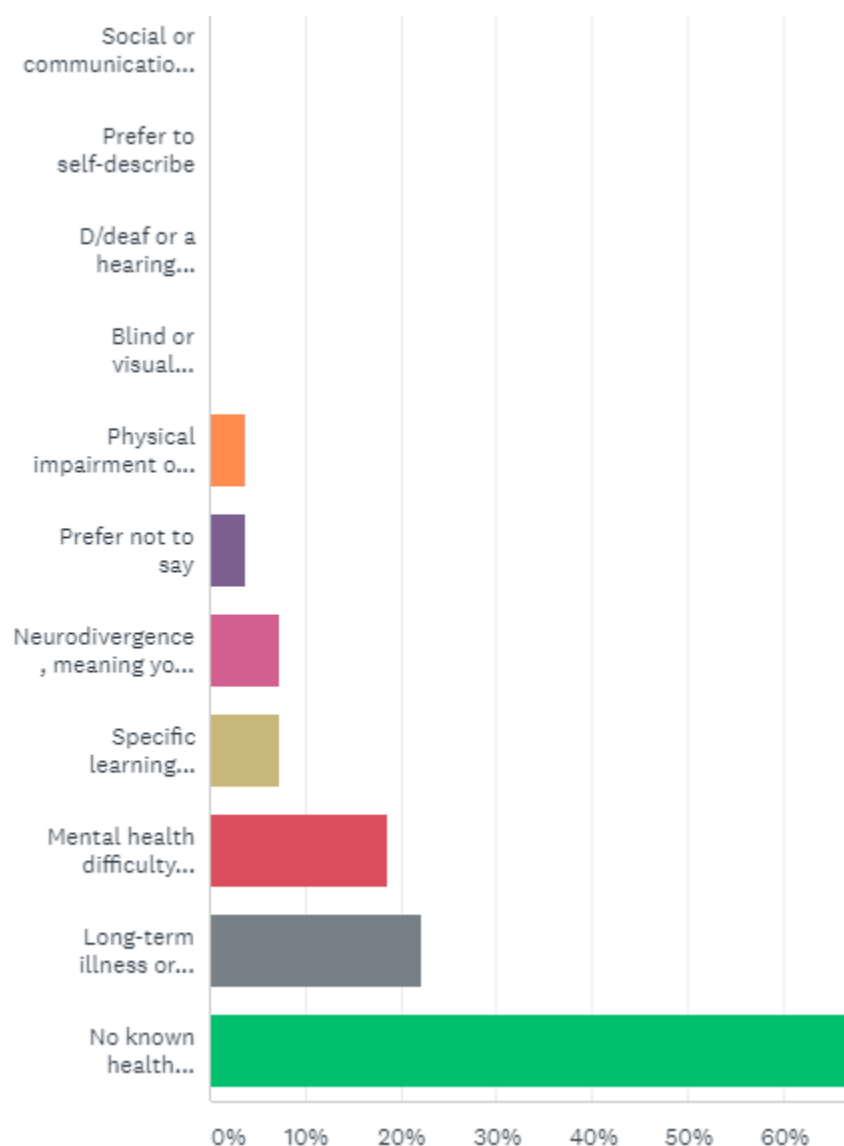
Intersex variation (28 respondents)

Participants were asked: ‘Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.’

100% (28) of respondents answered with a ‘No.’

Health conditions, impairments, learning differences or neurodivergence (27 respondents)

Participants were asked: ‘Do you live with a health condition, impairment, learning difference, or neurodivergence that has a substantial or long term impact on your day to day activities? (Select all that apply).’



0% of respondents selected social or communication condition, D/deaf or a hearing impairment, blind or visual impairment or 'prefer to self-describe.'

4% (1) have a physical impairment or mobility issues (e.g. difficulty using their arms, using a wheelchair)

4% (1) preferred not to say

7% (2) selected Neurodivergence, meaning your brain or mind works very differently from social views of what is 'normal' (e.g. AD(H)D, Asperger's syndrome/ other autistic spectrum condition, bipolar, dyscalculia, dyslexia, dyspraxia, Tourette syndrome)

7% (2) selected Specific learning difficulty such as AD(H)D, dyscalculia, dyslexia, or dyspraxia

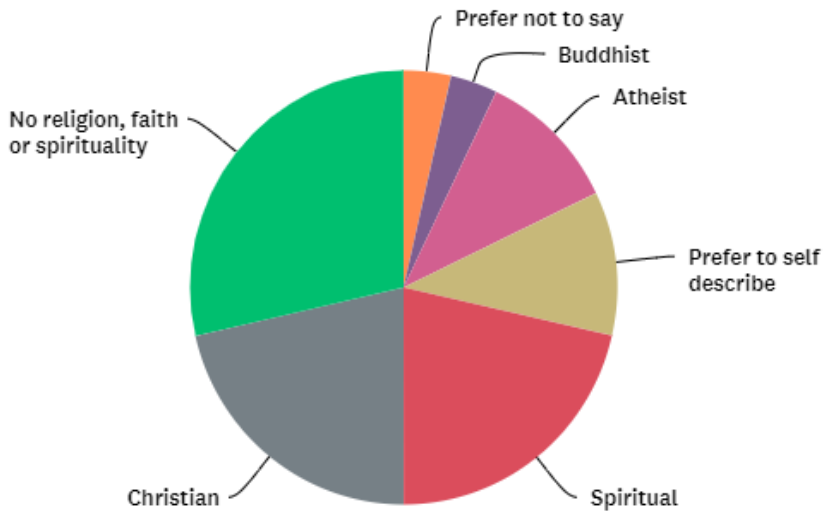
19% (5) have a mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)

22% (6) live with a long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)

67% (18) have no known health condition, impairment, learning difference, or neurodivergence

Religion, faith or spirituality (28 respondents)

Respondents were asked 'If you have a religion, faith, or spirituality, how would you describe it?' The most frequently selected option was 'no religion, faith or spirituality.'



0% of respondents selected Muslim, Hindu, Jewish or Sikh

4% (1) are Buddhist

4% (1) preferred not to say

11% (3) are atheist

11% (3) preferred to self-describe and gave their responses as Quaker, Buddhist Jew and 'no religion'

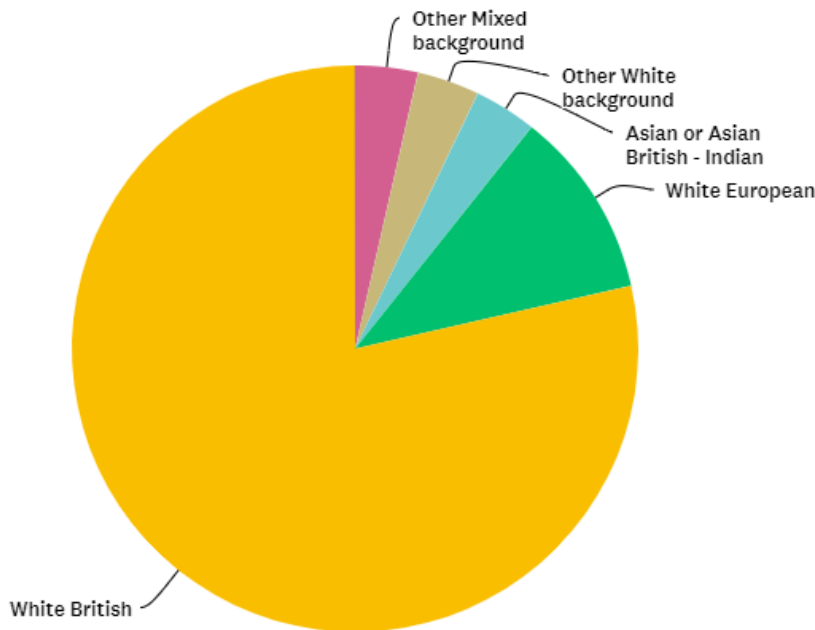
21% (6) selected 'spiritual'

21% (6) are Christian

29% (8) have no religion, faith or spirituality

Ethnic origin (28 respondents)

Respondents were asked to select from a list of terms to describe their ethnic background.



4% (1) selected 'Other mixed background'

4% (1) selected 'Other white background'

4% (1) selected 'Asian or Asian British – Indian'

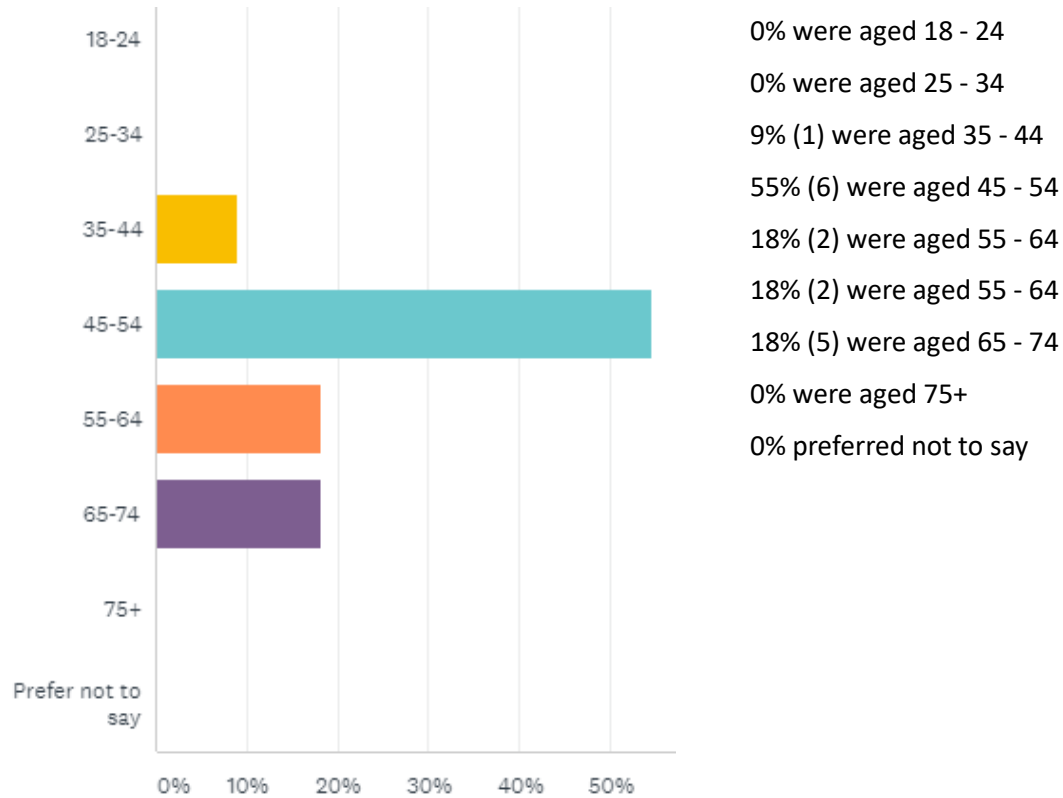
11% (3) selected 'White European'

79% (22) selected 'White British'

Demographic information from online survey: LGBTQ people affected by cancer

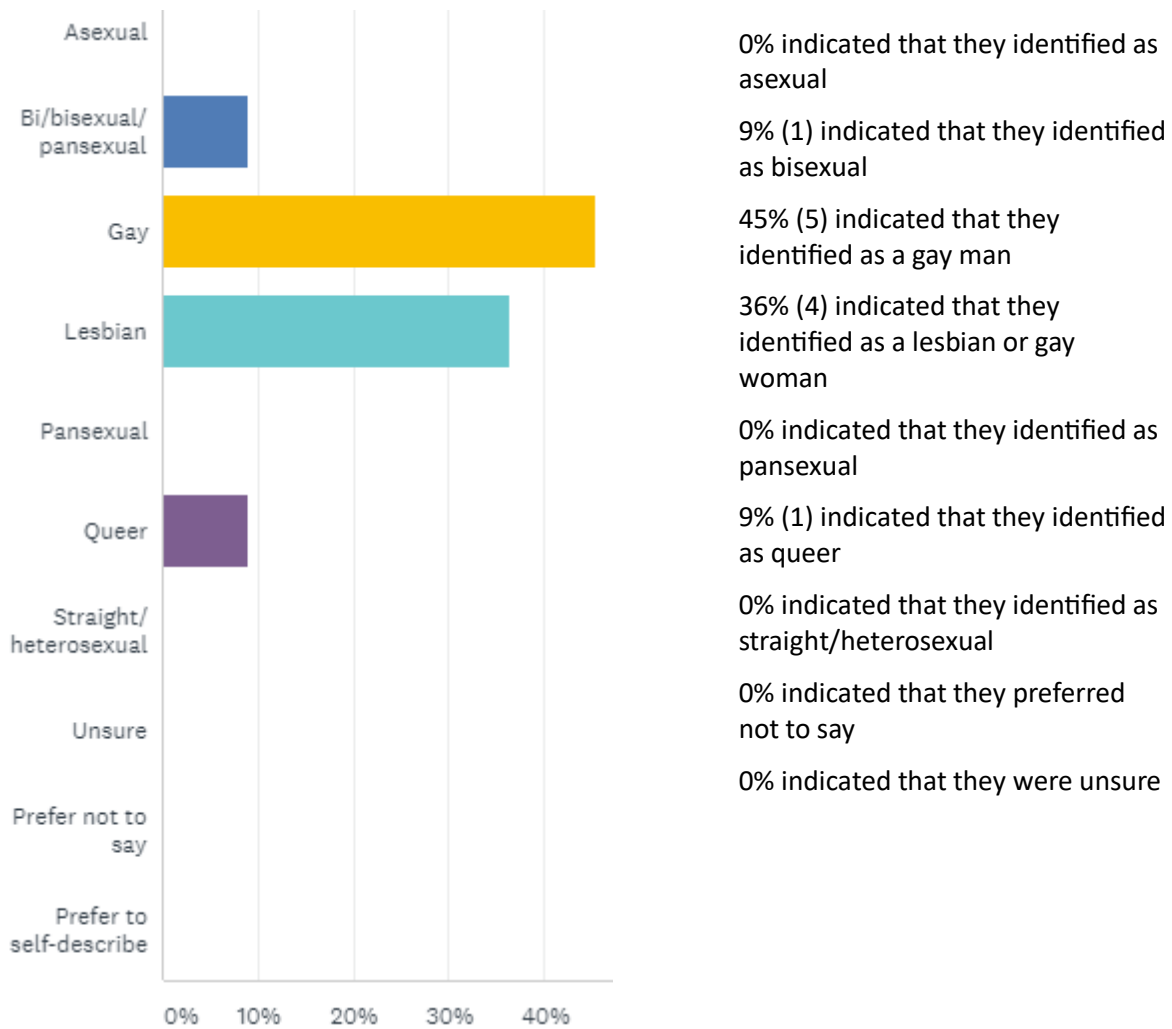
Age (11 respondents)

Participants were asked to select their age from a range of banded options. The age distribution showed the highest proportion of respondents to be between the ages of 55 and 64.



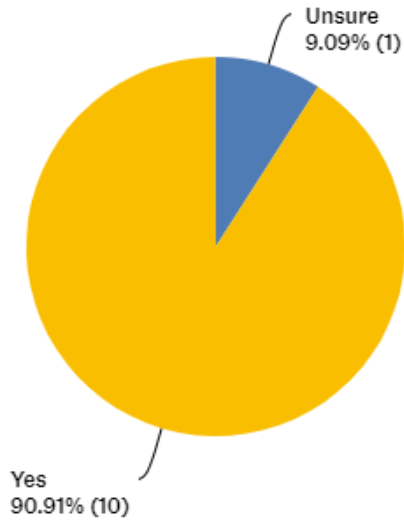
Sexual Orientation (11 respondents)

Participants were asked 'How would you describe your sexual orientation?' and were able to select more than one option.



Transgender status (11 respondents)

Participants were asked: 'Does your gender identity match the one you were assigned at birth?'

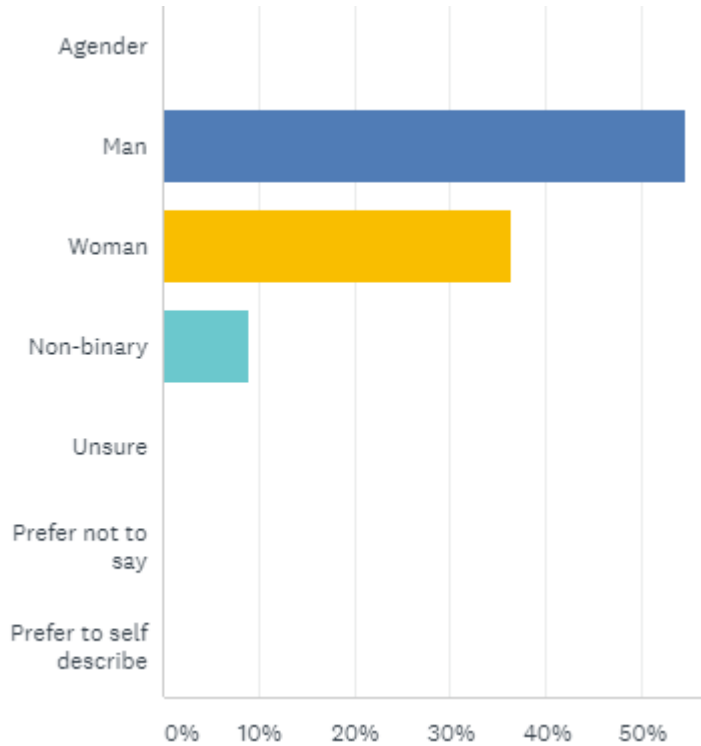


9% (1) of respondents were unsure whether their gender identity matched the one they were assigned at birth

92% (10) said their gender identity matched the one they were assigned at birth

Gender Identity (11 respondents)

Participants were asked to select which of the gender identities from the following list best described them: agender, man, woman, non-binary, unsure, prefer not to say or prefer to self-describe. Respondents could select more than one option.



0% of respondents identified as agender

55% (6) of respondents identified as man

33% (4) of respondents identified as woman

9% (1) of respondents identified as non-binary

0% of respondents identified as unsure or indicated that they preferred not to say, or preferred to self-describe

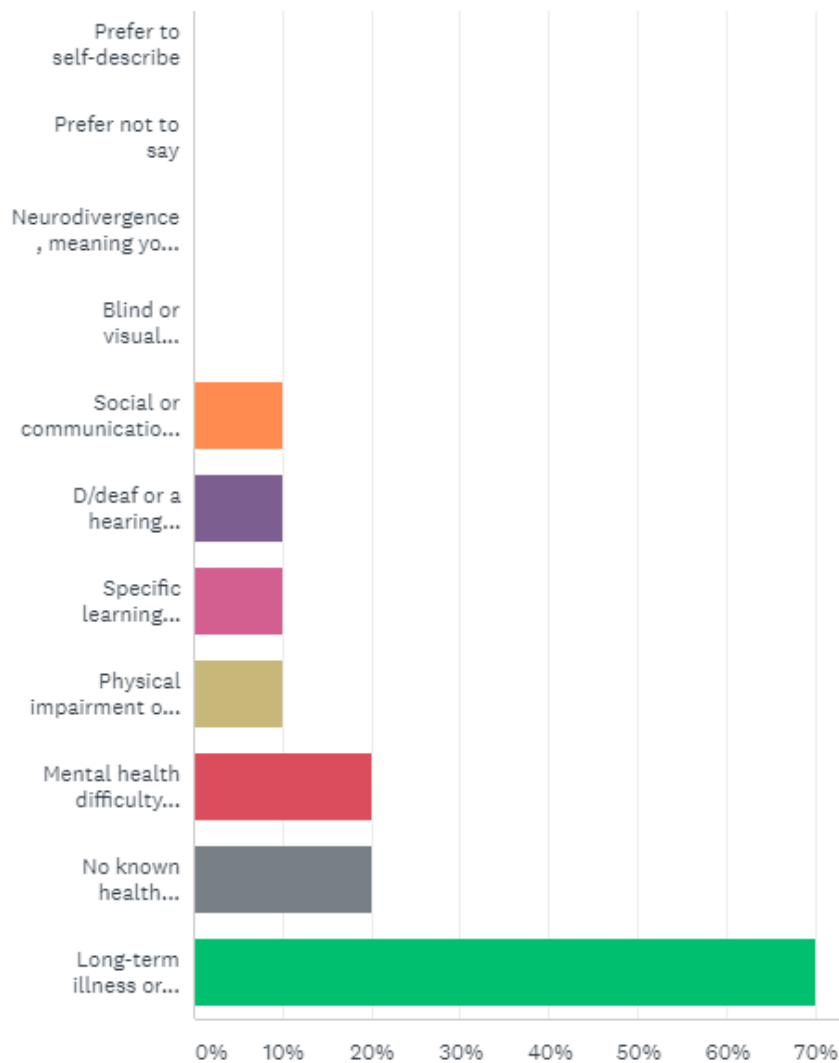
Intersex variation (11 respondents)

Participants were asked: ‘Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.’

100% (11) of respondents answered with a ‘No.’

Health conditions, impairments, learning differences or neurodivergence (10 respondents)

Participants were asked: ‘Do you live with a health condition, impairment, learning difference, or neurodivergence that has a substantial or long-term impact on your day to day activities? (Select all that apply).’



0% of respondents selected ‘prefer to self-describe,’ ‘prefer not to say,’ neurodivergence or blind or visual impairment

10% (1) selected Social or communication condition (e.g. a speech and language impairment, Asperger’s syndrome/ other autistic spectrum condition)

10% (1) selected D/deaf or a hearing impairment

10% (1) selected Specific learning difficulty such as AD(H)D, dyscalculia, dyslexia, or dyspraxia

10% (1) selected Physical impairment or mobility issues (e.g. difficulty using your arms, using a wheelchair)

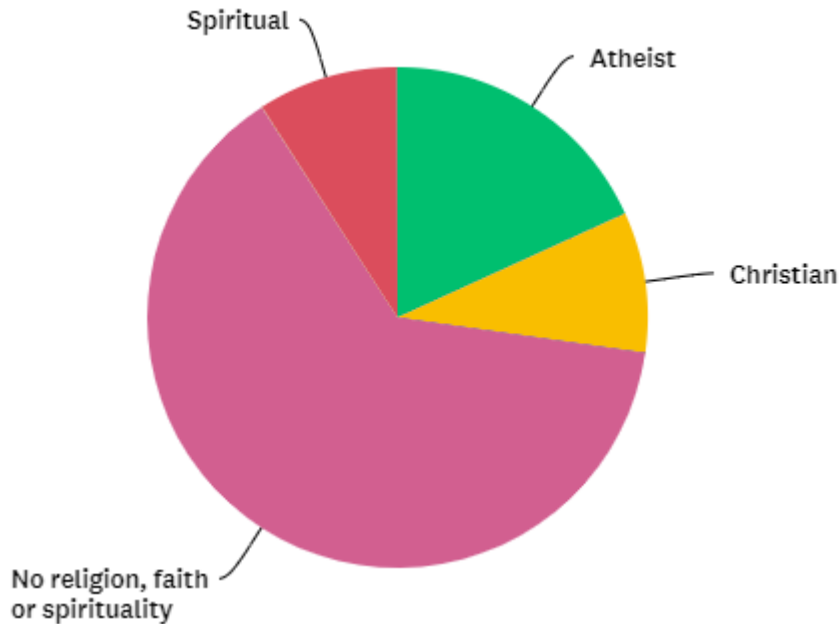
20% (2) have a mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)

20% (2) have no known health condition, impairment, learning difference, or neurodivergence

70% (7) live with a long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)

Religion, faith or spirituality (11 respondents)

Respondents were asked 'If you have a religion, faith, or spirituality, how would you describe it?' The most frequently selected option was 'no religion, faith or spirituality.'



0% of respondents selected Muslim, Hindu, Jewish, Buddhist or Sikh

0% of respondents selected 'prefer to self-describe' or 'prefer not to say'

9% (1) selected 'spiritual'

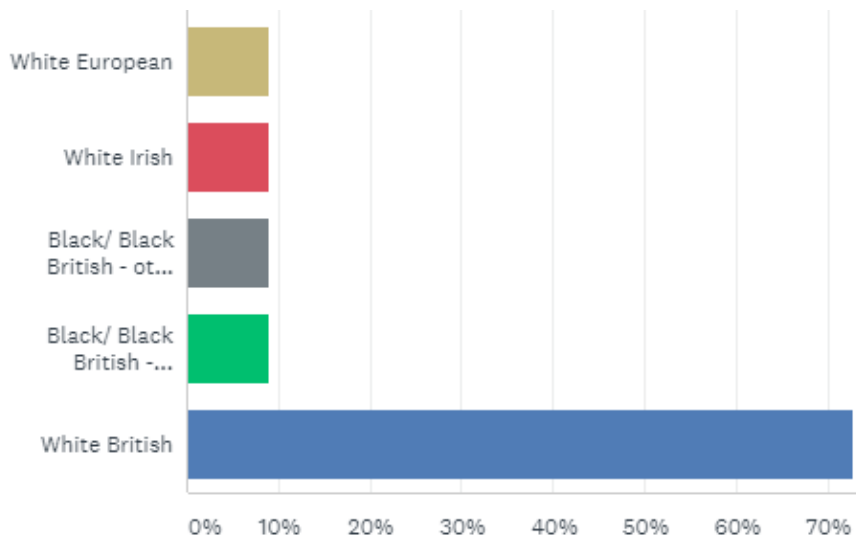
9% (1) are Christian

18% (2) are atheist

64% (7) have no religion, faith or spirituality

Ethnic origin (11 respondents)

Respondents were asked to select from a list of terms to describe their ethnic background.



9% (1) selected White European

9% (1) selected White Irish

9% (1) selected Black/ Black British - other Black background

9% (1) selected Black/ Black British - Caribbean

73% (8) selected 'White British'

