

Healthwatch Darlington

LGBT+ experiences of  
healthcare services

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February 2022



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## About Healthwatch Darlington

Healthwatch Darlington is the health and social care champion for people who live and work in the Borough of Darlington. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to people's feedback to improve standards of care.

We use feedback to better understand the challenges facing the NHS and other care providers locally, to make sure people's experiences improve health and care services for everyone.

We are here to listen to the issues that really matter to our local communities and to hear about people's experiences of using health and social care services.

We are entirely independent and impartial, and any information shared with us is confidential.



## Executive summary

Healthwatch Darlington wanted to understand the experiences encountered by the LGBT+ community, and how these experiences impact how the LGBT+ community use healthcare services.

We approached Arcus, a counselling and social support service, primarily developed for LGBT+ people, and agreed a set of questions for our survey which would provide a snapshot of experiences of health and care services in Darlington.

78 people took part in the survey which was supported by Arcus helping to distribute both online and hard copies in the community.

The experiences of those completing our survey indicate that there is not a consistent healthcare service offering to those who identify within the LGBT+ community. The experiences of those who took part in our survey reveal that it depends upon healthcare professionals encountered whether the experience is positive or negative.

Training and education of healthcare professionals was identified as important in providing more empathic practices and encouraging those who need support to go to the healthcare professionals who can help them.

We also asked about specific areas: HIV testing and maternity services.

There was a consensus that whilst progress had been made with HIV awareness, there was more that could be done in terms of education that would encourage those who needed to be tested to attend testing.

There was support for maternity services to be made more accessible with the use of inclusive language, helping those who need maternity care to feel supported and understood at this important time in their lives.

We will continue to work with Arcus and those in our community who often feel they are not listened to or understood, to raise awareness within the healthcare community and improve service offerings for all who need them.



## Introduction

Healthwatch Darlington is committed to meeting the duties set out under the Equality Act 2010, which outlines the legal framework for creating a fair and more equal society.

### **Meeting the Equality Act 2010 and Section 149: The Public Sector Equality Duty**

The Equality Act 2010, sets out a proactive duty on us to:

- Eliminate discrimination, harassment, and victimisation
- Advance equality of opportunity
- Foster good relations

To do this we need to understand the effect of policies and practices on equality and consider their impact on the whole population.

Under the Equality Act 2010, the relevant protected characteristics are:

- Age
- Disability
- Gender reassignment
- Pregnancy and maternity
- Race (including ethnic or national origins, colour or nationality)
- Religion or belief (or no belief)
- Gender (men, women, other)
- Sexual orientation
- Marriage and civil partnership (only concerning eliminating discrimination)

Those who have caring responsibilities for anyone with any of the above protected characteristics are also covered by the Act.

This vital piece of legislation protects people's rights in law and keeps all of us from unfair treatment and discrimination.

As an organisation whose sole purpose is to give a strong and powerful voice to people who often go unheard, the Equality Act 2010, serves as the minimum for our work. We believe that everyone should have a fair and equal experience using health and social care.

We recognise that some people and communities face compounding layers of disadvantage and discrimination, and we will ensure that our approach reflects the multiple inequalities that people face. Our work challenges discrimination and inequality.

To address health and care inequalities faced by LGBT+ people, it is important to know what affects them. We wanted to gain a better understanding of the lived experiences of lesbian, gay, bisexual, and transgender people, and people who identify as having any other minority sexual orientation or gender identity.



It is important to understand factors affecting the LGBT+ community regarding health and social care services, and the purpose of this report is to highlight health and care inequalities faced by LGBT+ people.

## Methodology

Healthwatch Darlington developed an online survey which we shared through our networks.

Arcus, a local counselling, and social support service primarily for LGBT+ people, helped us to distribute the survey amongst those who would be affected by its content.

We engaged people from the local community especially LGBT+ via an online survey with hard copies available if needed.

We attended 'Darlo Pride Weekender' seeking views and encouraging those we met to complete a survey.

We raised the profile of Healthwatch Darlington and how we can work with others such as Arcus to amplify the voice of those seldom heard in our communities.

We championed and promoted LGBT+ engagement and developed creative ways in which to continue collaborative approaches with the local population, particularly those unable to engage through traditional methods.

78 people took part in the survey.

## Demographics

Appendix one includes a full breakdown of the demographic profile of people who took part in this survey.



## Survey findings

We asked survey participants how they felt about healthcare providers communication in relation to their sexual and gender identity. We received a mixed response. Those who felt they were treated with respect were treated by healthcare professionals who used inclusive language and took the time to listen and understand the needs of their patients. Those who experienced more negative encounters said they felt judged, and that assumptions were made by healthcare professionals, and their correct gender not acknowledged.

While most respondents felt able to ask their healthcare professionals what they needed to, and that in return healthcare professionals asked them the right questions, there were a significant minority who did not feel this two-way flow of communication was effective. Examples of what they felt they should be asked are given in the 'Detailed finding's section below (questions 4 and 5).

Survey participants were asked about their thoughts on support structures in place. Over half said they would approach their GP / 111 when they needed medical attention, but the next most frequent response was to cope on their own. Family and friends were a reliable source of support, and the first people they would turn to for just over two thirds of respondents, before resorting to medical care.

When asked about HIV testing, 1 in 4 respondents felt there should be more education to enable people to make an informed decision about testing. There is still concern about society's stigma around HIV and the perceived shame of having the illness. Almost half understood the importance of being tested, a quarter wanted to make an informed decision based on sexual activity regarding the need to be tested, and the remaining quarter thought it was either not important or didn't know.

When asked about gender neutral language being used in maternity services, most respondents were supportive of the need for this. Two thirds thought it should be adopted locally, with the caveat from some that only gender specific terminology should be changed.

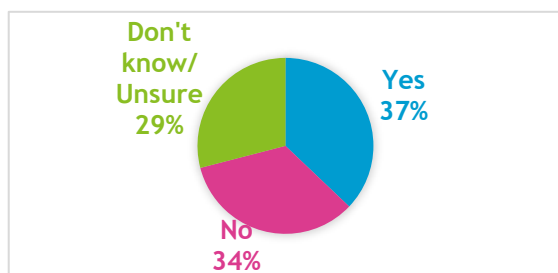
The general advice from survey participants was that more training around inclusivity, more respectful communication, awareness of differing needs, and compassion rather than judgement were the key areas that would benefit healthcare providers. More accessible information and services around sexual health were also called upon to improve the service offering to the LGBT+ community. Concerns about being misgendered were often raised throughout the survey.



## Detailed survey findings

### Communication and sexual / gender identity

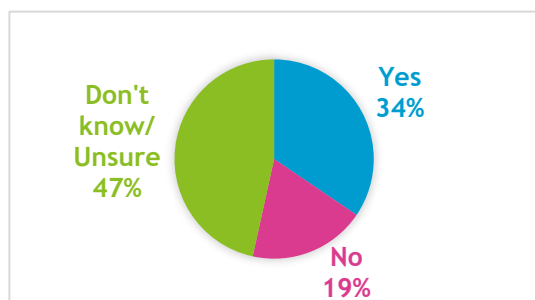
1. When you discuss you, your life, and what matters to you with health care providers, do you think your sexual or gender identity should be part of that discussion?



62 of the 78 survey participants responded to this question. Whilst there was a fairly even split of responses, there was a common theme in the comments provided which highlighted that it was dependent upon why they were seeing the health care provider, and whether it was relevant to the discussion. The use of correct pronouns was important. One respondent commented:

*“I think in order for this to happen in a way that would make LGBT+ individuals feel comfortable, there should be an effort made on health care providers part to ask questions of this nature in an open way. For example, not assuming heterosexuality when asking about sexual history, not assuming gender or checking pronouns and name on record are still correct and preferred. Little questions or approaches such as this lets me know I can be open and honest.”*

2. Do you feel they respect and understand your identity?



58 of the 78 survey participants responded to this question. Some provided comments to highlight it depended upon the healthcare professional they were dealing with. 34% of respondents provided a positive response. One respondent commented:

*“Some have been respectful and understanding (or are willing to learn / open about their lack of knowledge). Some have been less so.”*

3. How do they demonstrate this?

39 of the 78 survey participants responded to this question. Of those who had negative experiences, examples of demonstrating lack of respect and understanding included:

- Misuse of pronouns / misgendering.
- Feeling judged.
- Assumptions being made.

For those with positive experiences, examples of showing respect and understanding included:





- Using inclusive language.
- Taking time to listen.
- Taking time to understand.

Comments included:

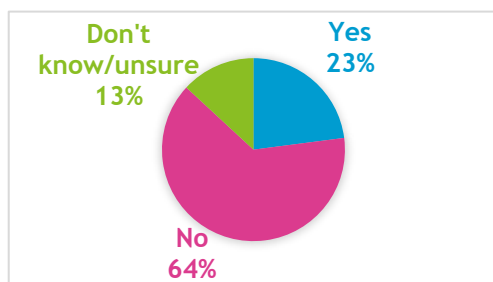
*“Misgendering, mannerisms, tone of voice and uncomfortable looks.”*

*“Passive aggressiveness, snide remarks, misgendering, failing to refer to gender services.”*

*“Some have sought out more information e.g., through CPD training, and been open about their learning process. Others have been quite ignorant / asked inappropriate questions.”*

#### 4. Do you have any questions that you think you'd like to ask your health care providers but don't?

61 of the 78 survey participants responded to this question.



39 said no, they asked what they wanted to.

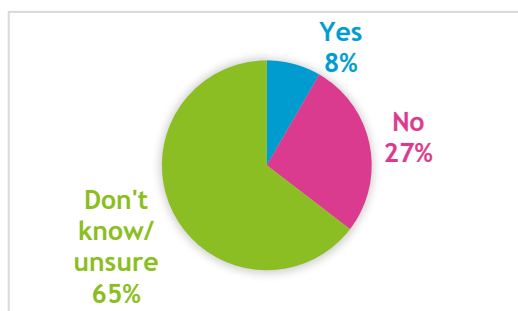
8 didn't know / were unsure.

14 said yes.

Below are the themes of questions they wanted to ask but don't.

- Having children
- Safety around sex, STI's etc.
- Advice on exploring their gender in a safe way when uncertain of their sexuality or gender.
- Why is there so little awareness of trans healthcare needs in Darlington, and little proactive engagement with LGBT communities around healthcare?
- Body / gender dysphoria.
- Up to date information for contraception and how to stay safe.
- Sexual health in LGBT relationships.
- Options for non-binary people.

#### 5. Are there questions you feel the health care providers don't ask you?



48 of the 78 survey participants responded to this question.

13 said no, they felt they were asked appropriate questions.

31 didn't know / were unsure

4 said yes, there were questions that health care providers didn't ask but should.



Below are the themes raised by those who said yes, didn't know or were unsure:

- The most common responses highlighted healthcare providers should enquire about the use of pronouns or how you identify.
- Mental health and barriers to people coming out.
- Sexuality.
- Asking questions to understand what situations would be potentially uncomfortable.
- How do you view your body or identity?
- Always ask rather than make assumptions.

#### 6. In your experience how does your identity affect your access to healthcare?

47 of the 78 survey participants responded to this question.

Over half of respondents told us their identity doesn't affect their access to healthcare.

Of those who felt that their identity did affect their access to healthcare, concerns within the comments included:

- Regularly being misgendered.
- Stress, confusion, and confrontation.
- Facing barriers to specialist healthcare and access to specific surgeries due to changes in contracts.
- NHS waiting times with the gender identity clinic.
- Lack of knowledge of health care providers with respect to gender dysphoria and transgender or non-binary people.
- Having to pay for treatment including IVF.

Comments included:

*"I have to give explanations often and it can get uncomfortable."*

*"It is a barrier for me accessing healthcare. I have to be really ill or in significant need to have to engage with health services in Darlington. I do not believe they understand or promote their services as LGBT inclusive at all."*

*"As a gay woman I am not asked about my reproductive health or my sexual health. It is always dismissed."*

## Support structures

#### 7. When you get ill, or are in pain, or your symptoms make life hard, what do you do?

54 of the 78 survey participants responded to this question. The top five themes mentioned in order of frequency mentioned were:

- Try medical help such as their GP or 111.
- Nothing except 'withdraw' and 'cry'.



- Find a way of coping on their own such as self-medication.
- Turn to family and friends.
- Take medication.

#### 8. Who do you turn to first?

56 of the 78 survey participants responded to this question. Common responses were:

- 75% would turn to a trusted family member or understanding friend.
- 10% would turn to their GP or other medical professional.
- Of the remaining responses, some would use google for information and some had no one to turn to.

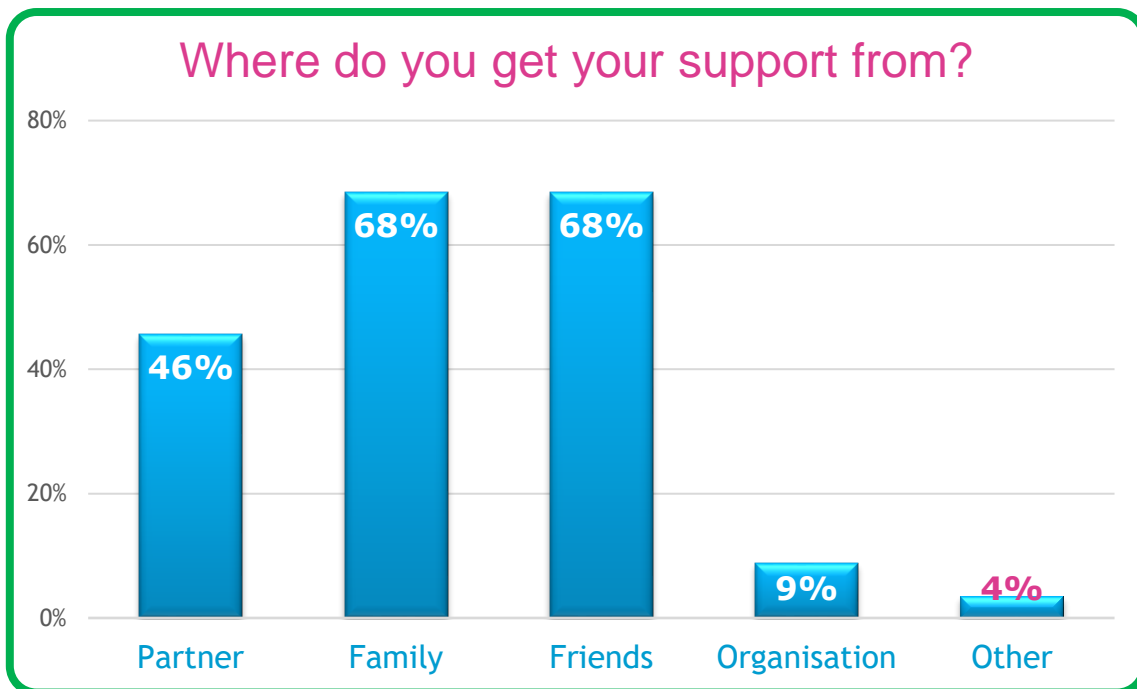
#### 9. Where do you get your support?

57 of the 78 survey participants responded to this question.

Participants were asked to choose one or more of the following options: Partner, Family, Friends, Organisation or Other.

For those who said organisation or other, common responses were:

- Young People of Pride (YPOP)
- Facebook and other online support forums.
- NHS.
- Face to face groups.
- School.
- Work colleagues



## National HIV testing

We told participants that regular testing for HIV helps to reduce the number of people living with undiagnosed HIV and those diagnosed late. Last year the HIV testing campaign returned with the successful creative ‘Give HIV the finger: a finger prick test is all it takes.’ The campaign encouraged people to test for HIV at home during the COVID-19 pandemic. We asked survey participants:

### 14. What are your thoughts on HIV/ AIDS as a life-threatening illness?

49 of the 78 survey participants responded to this question.

- About 25% felt there should be more education on HIV and felt they did not have the knowledge to make an informed opinion.
- About 20% understood there were treatments, and that early diagnosis would help, meaning a HIV diagnosis wasn’t necessarily life threatening.
- About 10% were concerned about the stigma that they feel is attached to HIV and the perceived shame of having the illness.
- About 5% mentioned safe sex being important.

Comments included:

*“Honestly, I feel completely uneducated on the disease. I feel there is still stigma around it, and it is still misunderstood (me included). To me it ties in with the rules around donating blood if you are a gay man, which I do not understand either.”*

*“I am old enough to have lived through the epidemic but given the right support this does not have to be life threatening.”*



### 15. How important is it to you to be tested for HIV?

46 of the 78 survey participants responded to this question.

- 48% said it was important.
- 26% said they would assess their risk first, as they did not feel testing was important if they were in a stable relationship or not sexually active.
- 15% said it was not important.
- 9% didn't know if it was important or not.

Comments included:

*"I think it is important and it should be checked when STI screening and it should be offered more freely to the public, so people can be tested in a discreet way."*

*"I'm not sure. Is it only a disease that affects men? there needs to be more education on it!"*

## Maternity services: broadening the language they use

We told survey participants that an NHS trust in the South of England have just broadened the language they use to support midwives providing care for trans and non-binary people who are giving birth. This work does not impact on other maternity services and staff are not being asked to stop using any language relating to women. Examples of gender inclusive language include: 'pregnant women and people', 'breastfeeding and chest feeding', 'mothers and birthing parents', 'human milk instead of breast milk'. The clinical guideline and model of care for trans and non-binary people is the first of its kind and will be made widely available to other maternity departments across the country.

We then asked survey participants:

### 16. What do you think about this?

53 of the 78 survey participants responded to this question.

The general consensus in the responses was positive and supportive, informing us that the more time taken to ensure language is gender inclusive is better for all.

However, there were concerns expressed that some anatomical terms such as 'breast', which were not gender specific did not need to change and changing such medical references could create unnecessary controversy.

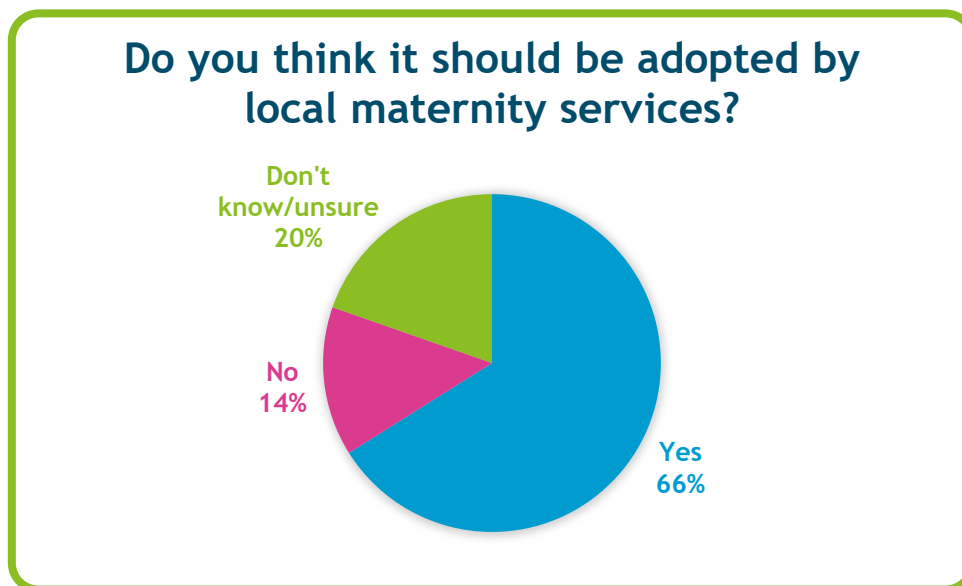
One respondent commented:

*"Any new use of language sounds strange at first until we get used to it. I understand people in general don't like change, but the fact is 650,000 people in the UK have gender dysphoria and we shouldn't experience exclusive use of language any more than other minority groups so I'm in favour of it."*



17. Do you think it should be adopted by our local maternity services?

56 of the 78 survey participants responded to this question.



Of those who responded, two thirds thought gender inclusive language, as explained in the green box above, should be adopted by local maternity services. Comments focussed upon inclusion and encouraging greater use of the service for trans and non-binary people.

*“It is just human decency to respect everyone no matter what.”*

Of those who said no, comments focussed on better terms (than those explained in the green box above) being employed, and not employing gender neutral terms when none were needed.

*“Terms like breast are gender neutral so I don’t think they would need altering.”*

## General

18. What should we teach healthcare providers?

47 of the 78 survey participants responded to this question. Responses were around the following attributes:

- Training / education: the real meaning of inclusivity.
- Respectful communication, including the importance of the correct use of pronouns.
- Awareness, not making assumptions.
- Compassion, not being judgemental.

One respondent commented:

*“Inclusivity training should be mandatory. The risks associated with discrimination, and exclusion, including the suicide rates, should be mandatory training.”*



19. If there was one thing that we could change, what would be most important to you?

45 of the 78 survey participants responded to this question. Common themes were:

- Better training / education / awareness of LGBT+.
- Sexual health information being more accessible.
- Healthcare services being more accessible including waiting times.
- More supportive and caring healthcare professionals.
- A more inclusive and respectful approach to the LGBT+ community.

Comments included:

*“Being able to mark my preferred pronouns on my medical record.”*

*“Making same sex sexual health information more accessible.”*

*“Making trans healthcare easier to access, i.e., reducing waiting times.”*

20. Is there anything else you'd like to add?

23 of the 78 survey participants responded to this question.

Most said there was nothing they wanted to add. One wanted greater investment in LGBT+ services. Another was happy with local services. One commented:

*“I would just like to say that it's validating to know that queer people are at least being asked about their experiences.”*

## Conclusions

The experiences of those completing our survey indicate that there is not a consistent healthcare service offering to those who identify within the LGBT+ community. The experiences of those who took part in our survey reveal that it depends upon individuals encountered whether the experience is positive or negative.

Training and education of healthcare professionals was identified as important in providing more empathic practices and encouraging those who need support to go to the healthcare professionals who can help them.

There are specific areas, HIV testing and maternity services, that could be made more accessible and encourage greater participation from those who need care.



## Recommendations

1. Healthcare providers to consider their training programmes with healthcare professionals and promote inclusivity training on a regular basis.
2. Promote greater awareness of HIV testing campaign within Darlington Borough.
3. Plan and implement changes to the maternity services to ensure the use of more inclusive language to those within the LGBT+ community who use their services.

## Response from Arcus

*“Thank you for giving us the opportunity to respond to this report. Firstly, it was a pleasure to be included in assisting with the circulation and promotion of this. Through the services we provide we are often given information from our service users about the inequalities and issues they face when accessing health care. It is a mixed blessing reading the report as it provides qualitative substance to the issues that we have had anecdotally raised to us, but it is a pitiful shame that these issues exist in the first place.*

*We recognise that there are some participants who felt comfortable going to their GP for support but find it worrying that some would not. The simple answer to this, perhaps, is training and education. Ideally it would be beneficial if all healthcare providers were to take advantage of LGBT+ Awareness Education that is widely available, through us and other organisations. Step two would be to communicate this to their patients and audience of benefit in the hope of breaking down this “barrier”.*

*Concerning the questions around HIV, we would agree that there has and to some extent still is, stigmatisation of this and other STI’s. Perhaps the answer here would be to raise the profile of sexual health services across healthcare providers in the hope that by proliferation it can be normalised and destigmatised.*

*Gender neutral language is critical, as is the delicate and sensible exploration of gender identity. When not using gender neutral language, assumptions are made, and these often lead to misunderstandings and contempt. When we are working with someone who is unwell it is often the small things that make big differences. By removing binary gender biased language on systems and within interactions, this allows for everyone’s true self to be nurtured. Imagine the scenario where we are actively trying to encourage groups to access services, but when they do, they are mis-gendered, dead-named or are unable to use their chosen pronouns and honourifics. This can, and sometimes does, send a message of non-acceptance and is another potential barrier that is easily rectified.*

*In conclusion Arcus would agree that the solution to the issues raised is education. Education for healthcare providers and then communicating this enlightened education to communities to encourage better and more rewarding participation”.*

**Andi Cull, Managing Director Arcus**





## Response from Tees Esk and Wear Valleys NHS

### Foundation Trust

*We recently received the Healthwatch Darlington LGBT+ Report February 2022 you produced and found it very interesting and extremely helpful.*

*We felt quite encouraged by the recommendations that you identified as we were already working towards two out of the three areas raised and we have incorporated the third in the training we provide, please see an explanation below:*

- **Healthcare providers to consider their training programmes with healthcare professionals and promote inclusivity training on a regular basis:**  
*We have been providing regular training sessions on working with LGBTQ+ service users and staff which we co- produced with our Rainbow staff network. We have encouraged staff to ask about demographics more and highlighted the benefits to patients of being asked these questions.*
- **Promote greater awareness of HIV testing campaign within Darlington Borough:**  
*Since receiving your report we have included this point in the LGBTQ+ training to raise awareness.*
- **Plan and implement changes to the maternity services to ensure the use of more inclusive language to those within the LGBT+ community who use their services:**  
*Where appropriate in our policies and procedures and perinatal mental health - operational policy we have introduced inclusive language and used a lot of the language that has been referenced in your report and have consulted with our Rainbow staff network on the changes to language.*

*Thank you again for generating this report.*

**Abigail Holder, Equality, Diversity and Human Rights Officer, People and Culture Directorate, Tees Esk and Wear Valleys NHS Foundation Trust**

### Next steps

Healthwatch Darlington will review progress to ensure the local and regional voice has been listened to and has influenced decision making.

We will continue to work with Arcus and others to champion change where needed and share good practice to drive up standards.

We will maintain our support to service users encouraging them to interact and share their views directly with providers.

We will encourage health and care providers to participate in high-quality LGBT+/ gender identity awareness training to develop the confidence to support the LGBT+ community and to challenge discrimination if it occurs.



## Acknowledgments

Healthwatch Darlington would like to thank all of the people who responded to our survey and shared their experiences to help improve services.

Thank you to Darlington Pride event for welcoming us as part of your celebration.

We would also like to thank Arcus who helped us reach a wide audience.

## Contact Information

### Healthwatch Darlington Limited

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Instagram: [@healthwatchdarlington](#)

### Arcus

Tel: **01325 978810**

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Post: **21b Wilbury Road, Hove, East Sussex, BN3 3JL**

Website: [www.arcuslgbt.com](http://www.arcuslgbt.com)

Training: [LGBT+ Awareness Training](#)

Facebook: [@arcussupport](#)

Twitter: [@ArcusLGBTcic](#)

Instagram: [@ArcusLGBTcic](#)



## Appendix one: Demographics

1. Age category	Participants	
Under 18	16	21%
18 - 24 years	7	9%
25 - 34 years	13	17%
35 - 44 years	9	12%
45 - 54 years	7	9%
55 - 64 years	4	5%
65+ years	1	1%
Did not answer	21	27%

2. Gender	Participants	
Female	34	44%
Male	7	9%
Non-binary	14	18%
Other	2	3%
I'd prefer not to say / no response	21	27%

3. Is your gender different from the sex you were assigned at birth?	Participants	
Yes	17	22%
No	37	47%
I'd prefer not to say / no response	24	31%

4. Ethnic background:	Participants	
Arab	0	
Asian / Asian British: Bangladeshi	0	
Asian / Asian British: Chinese	0	
Asian / Asian British: Indian	0	
Asian / Asian British: Pakistani	0	



Asian / Asian British: Any other Asian / Asian British background	1	1%
Black / Black British: African	0	
Black / Black British: Caribbean	0	
Black / Black British: Any other Black / Black British background	0	
Gypsy, Roma, or Traveller	0	
Mixed / Multiple ethnic groups: Asian and White	1	1%
Mixed / Multiple ethnic groups: Black African and White	1	1%
Mixed / Multiple ethnic groups: Black Caribbean and White	0	
Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background	0	
White: British / English / Northern Irish / Scottish / Welsh	36	46%
White: Irish	1	1%
White: Any other White background	3	4%
Another ethnic background	0	
I'd prefer not to say / no response	35	45%

5. Sexual orientation	Participants	
Asexual	2	3%
Bisexual	13	17%
Gay	3	4%
Heterosexual / Straight	11	14%
Lesbian	18	23%
Pansexual	6	8%
I'd prefer not to say / no response	25	32%

6. Religion or beliefs	Participants	
Buddhist	2	3%
Christian	7	9%



Hindu	1	1%
Jewish	0	
Muslim	0	
Sikh	0	
No religion	38	49%
Other	7	9%
I'd prefer not to say / no response	23	29%

<b>7. Marital or civil partnership status:</b>	<b>Participants</b>	
Single	28	36%
Married	12	15%
In a civil partnership	3	4%
Cohabiting	7	9%
Separated	0	
Divorced / dissolved civil partnership	3	4%
Widowed	0	
I'd prefer not to say / no response	25	32%

<b>8. Pregnant or have been pregnant in the last year?</b>	<b>Participants</b>	
Yes	0	
No	57	73%
I'd prefer not to say / no response	21	27%

<b>9. Carer, have a disability or a long-term health condition? (Please select all that apply):</b>	<b>Participants</b>	
Yes, I consider myself to be a carer	7	9%
Yes, I consider myself to have a disability	11	14%
Yes, I consider myself to have a long-term condition	16	21%
None of the above	32	41%
I'd prefer not to say / no response	3	29%