



An tSeirbhís Náisiúnta Scagthástála
National Screening Service

LGBT+ Cervical Screening Study

To examine the knowledge, attitudes, participation and experiences of lesbian and bisexual women, trans men, non-binary and intersex people with a cervix in cervical screening in Ireland

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Glossary of Terms

AFAB: Assigned female at birth.

Binary: Classification of gender into two distinct opposite forms e.g. female and male.

Bisexual: A person romantically, emotionally, physically, and/or sexually attracted to males/men and females/women. There may be a preference for one gender over others.

Cisgender: Used to describe a person whose gender identity is the same as the sex assigned to them at birth.

Come out: To tell others that you are LGBT+.

Gay: Someone who is romantically, emotionally, physically and sexually attracted to people of the same sex/gender. Mostly commonly applied to men, but it is also applied to women, although less frequently.

Gender dysphoria: The feeling of discomfort or distress that might occur in people whose gender identity differs from their sex assigned at birth or sex-related physical characteristics.

Gender expression: How someone presents their gender outwardly, for example by their choice of clothes; how they present their appearance and how they behave.

Gender identity: How someone perceives their gender.

Gender minority: A group whose sexual identity, orientation or practices differ from the majority of the surrounding society.

GMC: Gender minorities with a cervix.

FTM: (Transgender) female to male.

Heteronormativity: The assumption, whether by individuals or institutions, that everybody is heterosexual and/or that heterosexuality is superior to other sexual orientations.

Heterosexuality: Being romantically, emotionally, physically and sexually attracted to individuals of the opposite sex/gender.

Homophobia: A fear or hatred of homosexuals and or homosexuality.

HPV: Human Papilloma Virus.

Intersex: Used to describe people born with any of a range of physical or biological sex characteristics that do not fit traditional binary definitions for male or female bodies.

Legal sex: A person's legal sex/gender according to documents such as their birth certificate, passport or other records, depending on the jurisdiction.

Lesbian: Used to describe women who are romantically, emotionally, physically and sexually attracted to other women.

Non-binary: Gender identities that are not exclusively female or male.

Pansexual: Used to describe those attracted to people regardless of their gender. Pansexual people are sexually attracted to people of every gender identity.

Queer: An adjective used by some people whose sexual orientation is not exclusively heterosexual.

Sex: A biological term referring to certain combinations of gonads, chromosomes, external gender organs, secondary sex characteristics and hormonal balances.

Sexual orientation: the attraction people feel towards others based on their gender.

Transgender: An umbrella term for anyone whose gender identity or gender expression is different from the biological sex they were assigned at birth. Transgender individuals may identify as female, male, both or neither.

Trans: A commonly used shorthand version of transgender.

Transitioning: The process of transitioning from one sex or gender to another. This can be done by dressing differently, using makeup, changing how one speaks, changing hair, changing one's name, taking hormones, or having surgery. Transitioning does not always involve any or all of these steps and is ultimately about how an individual identifies themselves.

Transphobia: A fear or hatred of transgender people or transgenderism, or behaviours or beliefs that do not conform to binary role stereotypes.

Trans man: A person who was assigned a female at birth, who now identifies as a man.

Trans woman: A person who was assigned a male at birth, who now identifies as a woman.

Abbreviations

GP	General Practitioner
HCP	Healthcare Professional
HSE	Health Service Executive
STI	Sexually Transmitted Infection
NSS	National Screening Service

Executive Summary

This study focused on examining the knowledge, attitudes, participation and experiences of lesbian and bisexual women; trans men; non-binary and intersex people with a cervix in cervical screening in Ireland. The study was carried out between October 2020 and March 2021. Approximately 450 people who identify as LGBT+ took part in this study. It was carried out using an online survey, focus groups and stakeholder interviews. A Steering Group made up of stakeholder and community representatives oversaw the implementation of the study, conducted by Dr Maria Power of Community Consultants, Co. Waterford.

Respondents to our survey

- 88.9% were Irish, 70% lived in urban areas, 72% were between the ages of 25 and 45, and 91% had a third level qualification
- 59% identified as lesbian, 27% as bisexual and the remaining 14% identified as non-binary, trans, pansexual, queer or other.

Many of the findings of this Irish study are in line with the findings from several international studies with similar minority groupings. See Literature Review Section 3, page 9.

While many reported positive experiences of cervical screening, only 66.5% said they attended cervical screening regularly, which compares to 80% up-take by the general population. A study in the UK identifies 20% of non-attendance in their study of LGB women.

A finding which stands out across all the literature reviewed and from the survey and focus groups in this Irish study is the level of misinformation being communicated to the LGBT+ community, both by healthcare professionals and by the LGBT+ community. This study also found that there was a strong link between receiving a recommendation to attend for screening by your GP, practice nurse, friend or family member and attending for screening; this is also confirmed by international literature. However, in this study basic consultation practices were not followed in many cases, e.g. informing the service user about the procedure involved, letting them know what the test results would mean and by what method they would be received.

The main barriers to attending cervical screening were identified as:

- Heteronormative¹ assumptions being made by healthcare professionals
- Being asked heterosexual questions
- Fear of the test procedure

¹ Is the assumption or belief that heterosexuality is the default or normal mode of sexual orientation.

When exploring what would help improve attendance, the following were outlined:

- More targeted messaging and campaigns aimed at the LGBT+ community using multi-media tools and in partnership with the community.
- More LGBT+ friendly clinical environments and practitioners.

It would appear that attitudes to screening and knowledge of HPV is relatively good in the LGBT+ community, though a high number were unsure about the transmission of HPV and the cervical cancer signs and symptoms. Detailed responses are given in Section 4 page 22.

The stakeholders who participated in this study were very comfortable engaging with LGBT+ people but acknowledged the barriers faced by LGBT+ people and were not surprised by the findings.

Study findings are summarised in Section 7, page 30.

Recommendations are made to respond to the findings and these are summarised under the following headings:

1. Training and supports for Sample takers
2. Inclusion of LGBT+ community in cervical screening
3. Communication with LGBT+ community
4. Partnership work
5. Further research

Please see section 8 page 33 for details.

One caveat to the study is the fact that it all took place online, due to Government guidelines on COVID-19 restrictions. This may have led to some LGBT+ people being excluded from the study due to lack of access to online promotion; computer access, poor internet connection or other disadvantages.

1. Introduction

The HSE National Screening Service (NSS) was established in 2007 to oversee national screening programmes. These programmes aim to reduce morbidity and mortality in the population through early detection of disease and treatment, both of which greatly improve health outcomes. National screening programmes work at the population level, inviting healthy people to participate. However, it is acknowledged that many of the diseases screened for disproportionately affect certain populations. Those from socially disadvantaged backgrounds and socially excluded groups, find it more difficult to participate in these services, making it imperative that creative and innovative ways to engage with these populations are explored. Screening providers must take every opportunity to provide an equitable service and reduce health inequalities at all levels of service delivery. To achieve this they must engage with stakeholders to understand the needs of specific groups.

CervicalCheck invites all women in Ireland aged 25-65 years for free cervical screening, every three or five years depending on age. The aim of the programme is to detect abnormalities in the cervix that, if left untreated, could turn to cancer. The information about risks and the value of cervical screening for lesbian and bisexual women has in the past been conflicted until the role of Human Papilloma Virus (HPV) in causation of abnormal cells became clear and the recommendations around HPV screening, its use, effectiveness and who should be screened clearly included LGBT+ people and those with a cervix (*Public Health England, 2021*). Information provided on the HSE website stresses that anyone with a cervix is at risk from cervical cancer and should avail of regular screening (*HSE.ie, 2020*).

A review of international research has suggested that barriers for LGBT+² people accessing cervical screening include a reluctance to disclose sexual orientation to healthcare workers; fear of discrimination and negative experiences of heterosexism through heteronormative questioning; or assumptions of sexual orientation (*Henderson 2009, Fish 2009, Hunt and Fish, 2008a*).

One of the largest UK studies undertaken with lesbian, gay and bisexual (LGB) women in 2008 captured the health behaviour of over 6,000 LGB women. This study highlighted that 15% of LGB women over the age of 25 had never had a cervical screening test, compared to 7% of women in the general population (*Hunt and Fish, 2008*).

In 2011, a UK survey of 611 women (*Light and Ormandy, 2011*) showed that 51% of LGB women either never had a test, or did not have one within the recommended timescales. Further to this, the survey data indicated that 50% of LGB women eligible for screening had at some point failed to respond to a routine invitation for a cervical screening test, and of these 35% considered themselves less at risk of cervical cancer than a heterosexual woman.

In light of these and other international pieces of research and through the provision of workshops in LINC in 2019, it was agreed by the National Screening Service to examine the knowledge, attitudes, participation and experiences of LGBT+ people in cervical screening in Ireland.

LINC (see Appendix I) was significantly involved in all aspects of the study from holding initial meetings with the National Screening Service where it was suggested a study like this should take place; jointly drafting the proposal, actively and regularly participating on the Steering Group, inviting LGBT+ people to participate in all focus groups, facilitating, disseminating the survey and the provision of continued support throughout the project.

² For the purposes of this study LGBT+ as an acronym is used to represent the target groups of this study and include lesbian and bisexual women, trans men, non-binary and intersex people with a cervix.

Study Aim

The aim of this study is to examine the knowledge attitudes, participation and experiences of LGBT+ people in cervical screening in Ireland. The study was open to lesbian and bisexual women, trans men, non-binary and intersex people with a cervix.

Objectives

- To ascertain whether LGBT+ people attend for cervical screening
- To examine barriers to cervical screening for LGBT+ people
- To explore LGBT+ people's perceptions of HPV
- To explore key stakeholders' roles in engaging LGBT+ people in screening services
- To ascertain front line staff experiences/understandings of providing services to LGBT+ community
- To examine potential strategies for improving cervical screening participation and experience for LGBT+ people
- To make recommendations to CervicalCheck on best practice for engaging with LGBT+ people.

A Steering Group was set up to guide this study and included representatives from NSS, LINC, LGBT+ community and CervicalCheck, in addition to the consultant to this study. (See *members listed in Appendix I*). Dr Maria Power, Community Consultants carried out this study under the guidance of the Steering Group.

As part of the study, the process of engaging community representatives was documented and the following was highlighted by the representative: ***'I really enjoyed the whole process of the research study and learning a lot about how it works. I enjoyed being able to attend as a community member and give my input on the study, particularly on the language used and on how practices can be more inclusive. I've been asked to get involved in the promotion of the final report once it is published, which is something I am also excited to be involved in. All in all it was a great learning experience and it felt good to be actively involved in the process'***.

The study took place between October 2020 and March 2021.

2. Methodologies

This study used both quantitative and qualitative methodologies and specifically included:

- A literature review which examined approximately 40 research reports from around the world, in addition to reviewing six relevant Irish policy documents. All literature reviewed is listed on page 35.
- SurveyMonkey was used as the online platform to provide an accessible survey and several LGBT+³ social media platforms and databases were utilised to encourage maximum participation.
- The survey was designed and subsequently piloted with ten users prior to it being widely distributed.
- Interviews were carried out with four stakeholders, all of whom have a role to play with the LGBT+ community. A list of the stakeholders who were interviewed is listed in Appendix I.
- Two focus groups (one in Cork and one in Galway) were carried out, with 8 and 12 participants respectively who identified as lesbian or bisexual women, trans men, non-binary and intersex people with a cervix. The aim of the focus groups was to deepen the analysis of the early research findings and to access the lived experiences of the people the study aims to support. It was planned to host a third focus group in Dublin but there were difficulties getting the minimum number required to participate.
- A third focus group was facilitated by TENI (Transgender Equality Network Ireland). There were seven participants all aged 24-35 comprising trans men, non-binary and gender non-conforming people. All were assigned female at birth (AFAB).
- All findings were analysed and draft reports were prepared for the Steering Group to review. A final report was agreed in May 2021.
- All stages of the study were overseen by the Steering Group, including survey design and literature review: all draft reports were reviewed prior to finalising.

Sample Size

A sample size of 418 LGBT+ people responded to the survey. These people are of cervical screening age, i.e. 25-65 years and included lesbian and bisexual women, trans men, non-binary or intersex people with a cervix.

COVID-19

It must be noted that from the outset of this study, COVID-19 government guidelines were in place for the whole study period. This resulted in all interviews, focus groups and meetings taking place online or by phone. While engagement on the whole was excellent, online communication and exploration was limited and did not facilitate further in-depth discussion or promote a synergy effect that can naturally emerge from face to face contact. Working online can also exclude those who do not have access to a computer, internet or community word-of-mouth and can facilitate a higher participation of LGBT+ people who are younger and more educated.

³ LINC, TENI, Outhouse, Dundalk Outcomers, Amach Galway, LGBT Ireland.

3. Literature Review

Background

The purpose of this literature review is to provide a context for the qualitative research into the behaviours, beliefs, attitudes, influences and experiences of LGBT+ people with a cervix in Ireland as they relate to HPV cervical screening to prevent cervical cancer. While the majority of the literature available on the topic of sexual minority access to cervical screening relates to lesbian and bisexual women, this literature review also includes, where available, studies that report on the experiences of both lesbian and bisexual (LB) women and gender minorities with a cervix (GMC).⁴

The minority stress model posits that sexual minorities face unique and hostile stressors (e.g. homophobic victimisation) related to their sexual minority identity; consequently, these stressors have negative effects on their health (Meyer, 2003). This is a useful framework for understanding the impact of stigma and social exclusion on the health and wellbeing of minority groups. Research has demonstrated the higher levels of stress and distress caused to LGBT+ people because of factors such as presumptions of heterosexuality, homophobia or transphobia, and victimisation, as well as either concealing or 'coming out' about one's sexual orientation or gender identity. These stressors cause adverse health outcomes including mental and physical disorders, and may result in reduced social support (Maycock et al, 2009); increased health risk behaviours as well as negatively affecting access to healthcare resources (Burton et al, 2019).

Ireland's legislation endorses the Yogyakarta principles⁵ and the Public Sector Equality and Human Rights Duty 2014, which asserts binding international and national legal standards in relation to equality of sexual orientation and gender identity and on the rights to the highest attainable level of health. National equality policy prohibits discrimination on the grounds of sexual orientation and gender in the provision of services, and places an onus on public sector bodies and other service providers to promote equality and protect human rights (Crowley, 2015).

The Health Service Executive (HSE) has made commitments to promote and protect the rights of sexual and gender minorities in *The Health Service Executive National Service Plan 2015*, although this commitment is not included in the 2020 Plan. The *National Sexual Health Strategy 2015 - 2020* (Department of Health, 2015) identifies LGBT+ people as an 'at risk' or vulnerable group in relation to sexual health. Priority Action 4 of the *Strategy* states that the Department of Health will extend Human Papilloma Virus (HPV) vaccine to adolescent boys and potential at-risk groups (e.g. men who have sex with men). Cervical screening is not mentioned and there is no mention of HPV transmission between women who have sex with women, although there is a reference to herd immunity among females following widespread use of the HPV vaccine. The *National Cancer Strategy 2017-2026* (Department of Health, 2017), makes no specific mention of lesbian and bisexual women in the context of discussion of HPV and cervical cancer (or anywhere else). However, the strategy does state that its priority is to reduce health inequalities related to social deprivation, gender and age patterns.

Thus it is clear that there is at least a minimal, but growing, awareness among policy makers in Ireland that the LGBT+ population requires changes in healthcare services to ensure equitable access to good health and wellbeing.

4 Gendered Minorities with a Cervix (GMC) is a term used in the literature whereas we are using LGBT+ in this study.

5 The Yogyakarta Principles are a universal guide to human rights relating to sexual orientation and gender identity which affirm binding international legal standards with which all States must comply (Yogyakarta, 2006).

HPV and Cervical Cancer

Cervical cancer is the fourth most common cancer in women worldwide (*WCRF, 2020*) and the second highest cause of death due to cancer among women aged 25 to 39 years in Ireland. Each year in Ireland approximately 300 new cases are diagnosed and 90 people die of the disease (*HSE.ie, 2020*).

Cervical cancer is almost always caused by infection with a carcinogenic Human Papilloma Virus type (*WCRF, 2020; Smith et al, 2007*). Although in most cases the infection is relatively harmless, in some cases it can result in changes to cells in the cervix, which in time may develop into cancer if other environmental factors are present. These additional factors include: smoking; use of oral contraceptives for 5+ years; HIV and a weakened immune system; family history (possible genetic or shared environmental factors) or maternal intake of the hormonal drug diethylstilbestrol (DES) while pregnant; early sexual experience - increasing with the number of sexual partners; and may also include being overweight or obese, although there is limited evidence to support this hypothesis (*WCRF, 2020*).

Despite widespread common perceptions among health professionals, as well as service users, that HPV is only spread during heterosexual sex, medical advances such as enhanced HPV DNA amplification techniques (*Marrazzo, 2000*) and population studies (*Marrazzo, 2000; Henderson, 2009*), have shown that cervical cancer-related HPV can affect anyone with a cervix who has engaged in any sexual activity with another person, including sharing sex toys or skin-to-skin contact, regardless of the age, gender, or sexual orientation of either partner. For example, Marrazzo's study of women who have sex with women found HPV infection in 30% of the sample, including 19% of women who reported having no previous sex with men (*Hunt & Fish, 2008; Fish 2009; Light & Ormandy, 2011; Gatos, 2018; Marrazzo, 2000*).

HPV Screening

Cervical screening has been offered widely to Irish women since September 2008, with the launch of CervicalCheck – The National Cervical Screening Programme (*NSS, 2009*).

In March 2020, the Irish HSE introduced HPV cervical screening which looks for high-risk HPV virus strains which can cause cervical cancer and, if found, checks for abnormal (pre-cancerous) cervical cells.

Information provided on the HSE website stresses that anyone with a cervix is at risk from cervical cancer and should avail of regular screening (*HSE.ie, 2020*).

International evidence, spanning more than two decades and from a broad range of countries, demonstrates that LB women and GMC have significantly lower rates of uptake of HPV and cervical screening. This study sets out to examine the situation in Ireland against this backdrop.

The Population

“Lesbian and bisexual women comprise an invisible population: they are hidden as service users unless they disclose their sexual orientation.” (Fish, 2009)

A 2019 report which focused on LGB people in OECD countries found a rate of 2.7% of the population identifying as LGB, where estimates were available. This figure, however, fell at the lower end of a spectrum of country results, depending on the methodology used. Although they were as likely as men to claim an LGB identity, women were more likely to identify as bisexual than homosexual (OECD, 2019).

Transgender and non-binary rates in general are even more difficult to estimate, but where transgender estimates are available, figures range between 0.1% (Chile) and 0.3% (USA) (OECD, 2019). Todd *et al* (2019) cite figures from the 2015 U.S. Transgender Survey, which included 27,715 respondents, of whom 35% reported a non-binary gender identity.

The rate of intersex births also present some issues, mainly due to problems with definition. Estimates can range from approximately one in 5,000 newborns to one in 200, depending on which conditions are included (Garcia *et al*, 2020).

Numerous attempts have been made to quantify the LGBT+ population in Ireland as a whole, with the most recent governmental infographic suggesting a figure anywhere between 1.2% and 7% of the population of Ireland (Oireachtas, 2019).⁶ Given the difficulties in estimating the size of the population at the moment, this study will assume a figure somewhere in the middle of this range.

Risk factors

Fish’s review of worldwide literature identifies specific factors affecting lesbian women which increase their risks of cervical cancer (Bailey *et al*, 2000 cited in Fish, 2009 Knight and Jarrett, 2017).

Factors affecting LB women and GMC include:

- higher rates of smoking
- early age sexual contact and higher numbers of male sexual partners than heterosexual women, including men who have sex with men
- intravenous drug users.

Because HPV may take many years to develop into cancer, it can affect LB women and GMC who have ever had sexual contact with any person of any gender.

Light and Ormandy (2011) highlight the increased prevalence of cervical cancer and higher death rates from the disease among those LB women living in less affluent regions, compared with their counterparts in more affluent areas.

Curmi *et al* (2015) cite findings which indicate that lesbian women have higher rates of obesity, which although not a factor in developing precancerous cervical cells, were found to correlate with higher rates of developing cervical cancer.

⁶ A question on sexual orientation is being considered for the Irish Census 2026 and was tested in the Quarterly National Household survey for quarter one 2019 (Holland, 2019).

Gatos (2018) notes that less than one in 10 respondents in the 2015 U.S. Transgender Survey who were identified as female at birth had a hysterectomy to remove the uterus and cervix: therefore nine out of 10 require cervical screening. Connolly et al (2020) explore the effects of hormone therapy on cervical screening outcomes and show that gender minorities assigned female at birth were 11 times more likely to receive inadequate (ambiguous/unsatisfactory) cervical screening results than cisgendered women. Another study also found that higher risk was associated with a longer period of time taking testosterone or a higher body mass index (*Peitzmeier, Reisner, Harigopal, & Potter, 2014 cited in Gatos, 2018*).

In Ireland, the HSE lists the risks of developing cervical cancer as including smoking, having a weakened immune system, and maternal intake of the hormonal drug diethylstilbestrol (DES), while pregnant (*HSE.ie, 2020*).

The *National Cancer Strategy 2017 - 2026* states that health inequalities in general are associated with poor symptom awareness, delayed presentation and low uptake of services, including screening (*Department of Health, 2017*). This relates to another factor that emerges from the literature, which is where women who have sex with women underestimate the risk of developing cervical cancer, often as a result of misunderstandings about how HPV is transmitted.

One of the main findings across the literature is that a sizeable minority of LB women are more likely to consider themselves at lower risk of cervical cancer than heterosexual women (*Fish, 2009; Knight & Jarrett, 2017*). Light and Ormandy (2011) reported one in five respondents holding the belief that LGB women were at lower risk from cervical cancer than heterosexual women. Carter *et al* (2012) assert that in their experience this myth has been believed and relayed by both health professionals and lesbian and bisexual women. Indeed many women in their study were reported to have had to assert their right to screening against arguments from health professionals that they are not eligible because they are not at risk.

A further risk factor was identified in a survey of young women from the general population in the UK, which found that 70% of 25 to 29 year olds do not believe that cervical screenings reduce a woman's risk of cervical cancer (*Jo's Trust, 2017*). Since cervical cancer is largely preventable through regular screening, low uptake of screening services will increase the risks of developing cervical cancer in a population.

Rates of cervical screening

Although there are no official statistics on whether LB women and GMC in Ireland are accessing cervical screening in the same numbers as cisgender heterosexual women, the National LGBTI+ Inclusion Strategy (*Government of Ireland, 2019*) acknowledges that LGBT+ people are less likely to engage with health interventions and screening programmes in general. The general findings on poor attendance correlate with evidence from other jurisdictions, which strongly suggest that LGBT+ individuals are less likely to attend for regular cervical screening, and some do not attend at all. Gatos (2018) also notes that the frequency of screening is lowest among minority group people who do not have a regular healthcare provider, who have lower incomes and have lower educational attainment.

Hunt & Fish (2008), in a UK survey of 6,178 LB women aged between 14 and 84 years, found that LB women over the age of 25 years were more than twice as likely to have never had a cervical smear test (15%), compared to women in general (7%).

The following year Fish (2009) found in a review of worldwide research on cervical screening in LB women that they were far less likely to attend regular cervical screening than their heterosexual counterparts, and that this was even more marked among those who had never had sex with a man.

Although participation rates were shown to increase with age, LB women were up to 10 times less likely to have been screened in the previous three years, with rates of having never been screened at all ranging from 12% to 17% in the studies analysed.

Almost one in five of the 507 LGB women aged 25-64 years surveyed in the North West of England by Light and Ormandy (2011) had never been for a test, with fewer than half having accessed screening within the previous three years as per national recommendations. Half of respondents had at one time or another failed to respond to an invitation for screening.

Reiter et al (2015) looked at cervical screening uptake among young LB women aged between 21 and 26 years in the USA, and found that almost one third had not been screened in the past three years, compared with just 16% among the general population of women, while 24% had never been screened at all. Those women who identified as lesbian were less likely to have been screened than those who identified as bisexual.

Johnson's study (2016) noted that LBQ women who received a recommendation to get tested from their healthcare provider were more than four times as likely to screen routinely than those who did not (*Johnson et al, 2016*).

Other studies show that transgender men are more likely to have abnormal results compared with cisgender women, possibly related to their lower rates of screening and delaying return appointments after initial abnormal results. One study found that it took five times longer for FTM (Female to Male) individuals to return, compared with cisgender women (*Peitzmeier, Reisner, Harigopal, & Potter, 2014 cited in Gatos, 2018; Connolly, 2020*).

Barriers to cervical screening

Research has revealed a range of factors influencing levels of uptake, some of which are common to the general population, such as:

- fear of the test or of the results
- age
- convenience
- socio-economic factors
- provider's recommendation
- trauma
- female genital mutilation (FGM)
- sexual activity.

While some are specific to the LGBT+ population or to sub-groups within it, broadly speaking the barriers can be broken down into two parts: attitudes and beliefs among the population itself; and their experiences and expectations of health services.

Attitudes and beliefs that hinder uptake

The studies included in this review showed uptake rates were influenced by the beliefs and attitudes of the respondents in relation to a range of issues.

These issues include:

- a lack of knowledge of screening guidelines
- the exchange of misinformation
- stigma when seeking information
- misunderstanding of the risks
- fear of pain
- fear of penetration
- lack of time to book a test
- having fewer cues for routine screening in the absence of regular checks necessitated by contraception, pregnancy and birth control.

(Tracy et al, 2010; Curmi et al, 2014; Johnson et al, 2016; Knight & Jarrett, 2017; Hunt & Fish, 2008; Fish, 2009; Carter et al, 2012; Connolly et al, 2020; Light and Ormandy, 2011; Jo's Trust, 2017)

Marlow et al (2019) researched attitudes towards cervical screening among older LB women from lower socio-economic and minority ethnic group backgrounds and found that many had poor understanding of the procedure, while others had previously had negative experiences.

Fish (2009) found that lesbian women were likely to believe their risk of cervical cancer was lower than that of women who have sex with men, and therefore often felt that screening was unnecessary for them. Light and Ormandy's (2011) North-West England survey of 609 LGB women also revealed that one in five respondents believed that LGB women had a lower risk of cervical cancer than heterosexual women.

The study showed that myths of lower risk and no risk had been communicated through friends, family and within the LGB community as well as by healthcare providers, and directly negatively impacted uptake among a large minority of respondents. Among the cohort of 47 women who were uncertain, or believed screening was not necessary for LGB women, 37 had been told they did not need to be tested and based on this information, and 28 of them had never had a test.

Some studies of trans men found evidence that attending for screening may cause degrees of distress related to gender dysphoria, as it requires removal of clothing, prostheses and binders, as well as forcing a focus on an essentially female part of the anatomy (Connolly et al, 2020). However, a participant in one study cited by Connolly suggested that the possibility of receiving a positive result with the devastating effect that might have on a transgender man could act as a motivator for screening (Peitzmeier et al, 2017 cited in Connolly et al, 2020).

Experiences of and attitudes of LGBT+ people towards healthcare services

A number of barriers relating to attitudes and experiences of healthcare services emerged from the literature.

These factors include:

- unwelcoming environments (*Johnson et al, 2016; Knight & Jarrett, 2017*)
- fear of homophobia, transphobia and discrimination (*Curmi et al, 2016; Knight & Jarrett, 2017*)
- mistrust of the healthcare system (*Johnson et al, 2016*), which may also correlate with not coming out to one's healthcare provider (*ibid; Tracy et al, 2010; Connolly et al, 2020*).

Fear of, or actual, experiences of discrimination and homophobia can impact negatively on the relationship with the healthcare provider, and this can act as a barrier to getting crucial information and to being prompted to attend regular screenings (*Tracy et al, 2010*). On the other hand, as found in Johnson's study cited above, LBQ women who received a recommendation to get tested from their healthcare provider were more than four times as likely to routinely access screening than those who did not receive such a recommendation, showing how important proactive advice can be in improving outcomes for vulnerable patients (*Johnson et al. 2016*).

The prevalence of heteronormative assumptions among healthcare providers. Carter *et al* (2012) found that their participants felt forced to make a choice between coming out or not coming out and having it assumed they were heterosexual. Knight and Jarrett highlight a number of ways in which healthcare settings might feel unwelcoming to LB patients, such as websites and brochures featuring only heterosexual couples and families, forms with no gender neutral space for partners, as well as a lack of knowledge about health issues specifically affecting this population. Some of the consequences of this include patient hesitancy to initiate frank conversations about sexual practices; delaying or avoiding necessary health care and overall poor communication between patient and provider resulting in poor health outcomes.

Hinchliff *et al* (2005) explored **the attitudes of GPs** in relation to discussing healthcare with their LG patients and found that GPs were likely to assume heterosexuality unless explicitly told otherwise. Among the sample there was also widespread ignorance, embarrassment and assumptions made about LG lifestyle and sexual issues, while some GPs expressed fears about using inappropriate language and a minority displayed homophobic attitudes. The authors concluded that a patient's LG identity was experienced as a barrier to discussing sexual health matters among almost half of the sample of GPs.

Hunt and Fish (2008) cited **high levels of misinformation about HPV and cervical cancer from healthcare providers to LB women**, where among those who said they had not been screened, one in five women said that they had been told they are not at risk, while one in 50 had been refused a test.

Half of the respondents in the study had experienced discrimination or bias in the healthcare system during the previous year, and half had not disclosed their sexual orientation or behaviour to their GP. When they did come out to healthcare workers, some said they were ignored, while others had been the subject of inappropriate comments.

Among the LGB women included in Light and Ormandy's study, many had been given misinformation by health service providers as well as by friends, family and from within the LGB community. **Fourteen per cent had been discouraged or refused a test by a health professional on the basis of their sexual orientation.**

Hermann *et al* (2016) in *The Report of the 2015 U.S. Transgender Survey*, found that 42% of transgender men and one quarter of non-binary people had negative experiences with healthcare providers in the previous year, and almost one third of respondents were not out to any of their healthcare providers. Gatos highlights the difficulties presented by the gynaecological examination for some transgender men as the effects of taking supplemental testosterone may make vaginal penetration more difficult and uncomfortable (Gatos, 2018).

Connolly *et al* (2020) note that although the UK health service has a well-established cervical screening service, only those who have a female gender marker on their records are sent invitations to attend, thus risking excluding female to male transgender individuals as well as non-binary people with a cervix. The importance of having a culturally competent provider was paramount to the transgender men included across the studies. **However, the authors found wide variation among healthcare providers in levels of knowledge and comfort of providing cervical cancer screening to GMC.**

In Ireland

O'Connor *et al* (2014) demonstrates the critical role of GPs within the general population of women's uptake of cervical screening, identifying four sub themes which influenced rates of access: the GP's attitude; whether prompted by the GP; the degree of trust in the GP and the quality of the relationship with the GP.

Crowley's 2015 *Rainbow Report* on Irish LGBTI health needs and health sector responses in the South East of Ireland notes higher reported rates of discrimination in the health system among lesbian and bisexual women and bisexual men in Ireland compared with their European counterparts. This was highlighted in the results of a survey of 93,079 people over the age of 18 who identified as LGBT.⁷

A study of GPs included in the *Rainbow Report* indicated that they are not meeting the healthcare needs of the LGBTI community. In the majority of cases, healthcare providers are unaware of the specific health needs of LGBTI people or of the need to provide tailored approaches to ensure that their health is taken care of. A survey of GP practices in the South East region found that of the 64 respondents, 50 of the 64 had no LGBTI training, and most of the 14 who did only had it as part of a larger training.

Most respondents had taken no steps to make their practice openly LGBTI-friendly nor did they have practice guidelines for equality and diversity in the treatment of LGBTI people. In fact, most adopted an equal treatment approach and were not open to implementing special measures for LGBTI patients, with one respondent stating that they found the survey "...offensive. We do not discriminate or favour patients based on sexuality, gender, career, money, etc." Most reported that they felt that their practice was open to all and everyone was treated the same, and that there was no need to communicate this to particular groups, with one respondent referring to 'medical ethics' requiring equal treatment of patients. Some cited staff and existing patients as barriers to increasing visibility of LGBTI issues in their practice.

The main findings were that General Practitioners are committed to an approach that is based on "treating people the same, treating people equally and/or treating people non-judgmentally" which may result in the specific needs of LGBTI people being overlooked in the public profile of the practice (whether LGBTI people feel welcome), the proactive inclusiveness of practice policy, training and professional development, and programme development (Crowley, 2015).

The ICGP Guide for Providing Care for Lesbian Gay and Bisexual Patients in Primary Care: Quick Reference Guide 2020 identifies five elements of good practice for providers:

- Stay informed on LGB health issues
- Don't assume patients are heterosexual
- Acknowledge when patients disclose they are lesbian, gay or bisexual
- Take a gay-affirmative approach and challenge bias
- Demonstrate that your practice is LGB friendly.

⁷ EU LGBT Survey, European Union Fundamental Rights Agency, 2013 cited in Crowley, 2015.

The *National LGBTI+ Inclusion Strategy* (Government of Ireland, 2019) sets out goals in relation to the provision of services to LGBT+ people, including the provision of training for healthcare providers and practitioners in understanding the identities and needs of the LGBTI+ service users, and avoiding heteronormative assumptions (Goal 14). The Strategy acknowledges the need to include the sexual health needs of the LGBTI+ community in the *National Sexual Health Strategy* (Goal 15.1), and commits to ensuring that “a holistic, person centred approach to sexual health, covering all genders as well as risk factors, is adopted” through the Foundation Programme in Sexual Health Promotion for professionals (Goal 15.6).

In 2019, in relation to the provision of inclusive healthcare, the HSE developed an e-learning resource, ‘LGBT+ Awareness and Inclusion Training: the basics,’ for all staff within the HSE and relevant partner organisations, to improve understanding and suggest simple changes to everyday practice to enhance the services they provide to LGBT+ people (*HSELand, 2019*). The ICGP Guidelines states that accomodating different is crucial to improve cervical screening services for lesbian, gay and bisexual women and gender minorities with a cervix. Ongoing data collection and monitoring of uptake and experiences will enable services to adapt to changing needs (*ICGP Guidelines, 2020*).

Strengths and limitations of the literature review

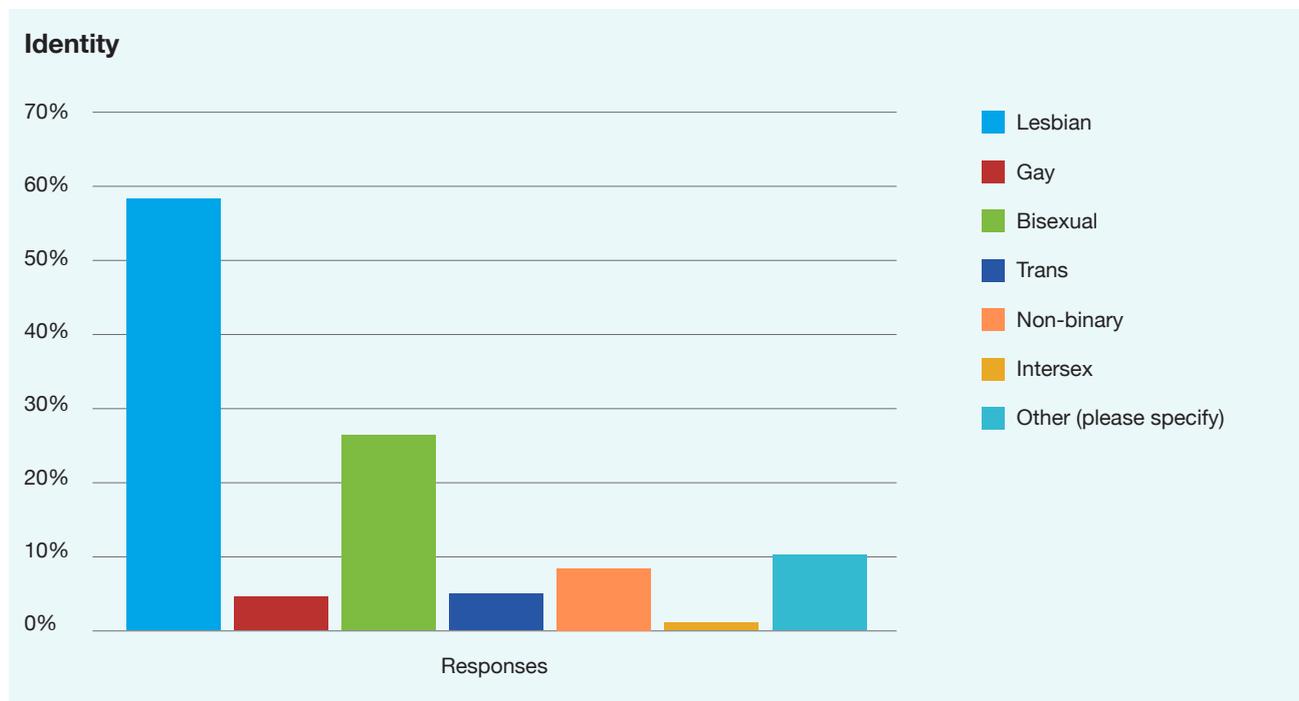
A body of international research has been included in this literature review as studies of the population in Ireland are scarce. Findings from other countries might not apply to the situation in Ireland in all cases, but indicators in Ireland, where they exist, appear to correlate with findings from worldwide literature.

4. Survey Results

Four hundred and eighteen people completed the online survey, which ran for five weeks between February 8th and March 12th 2021. This was a higher response than expected and therefore builds confidence in the results. The main survey results are highlighted below, with visual graphs for some questions.

Background Information

Of the 418 respondents, 88.9% stated that their nationality was Irish with a range of other nationalities from across the world making up the balance. In terms of identity, 59% identified as lesbian, 27% as bisexual and the remaining 14% identified as non-binary, trans, pansexual, queer or other. The majority of people who responded to the survey were aged 25-35 (48%) followed by age 36-45 (24%).

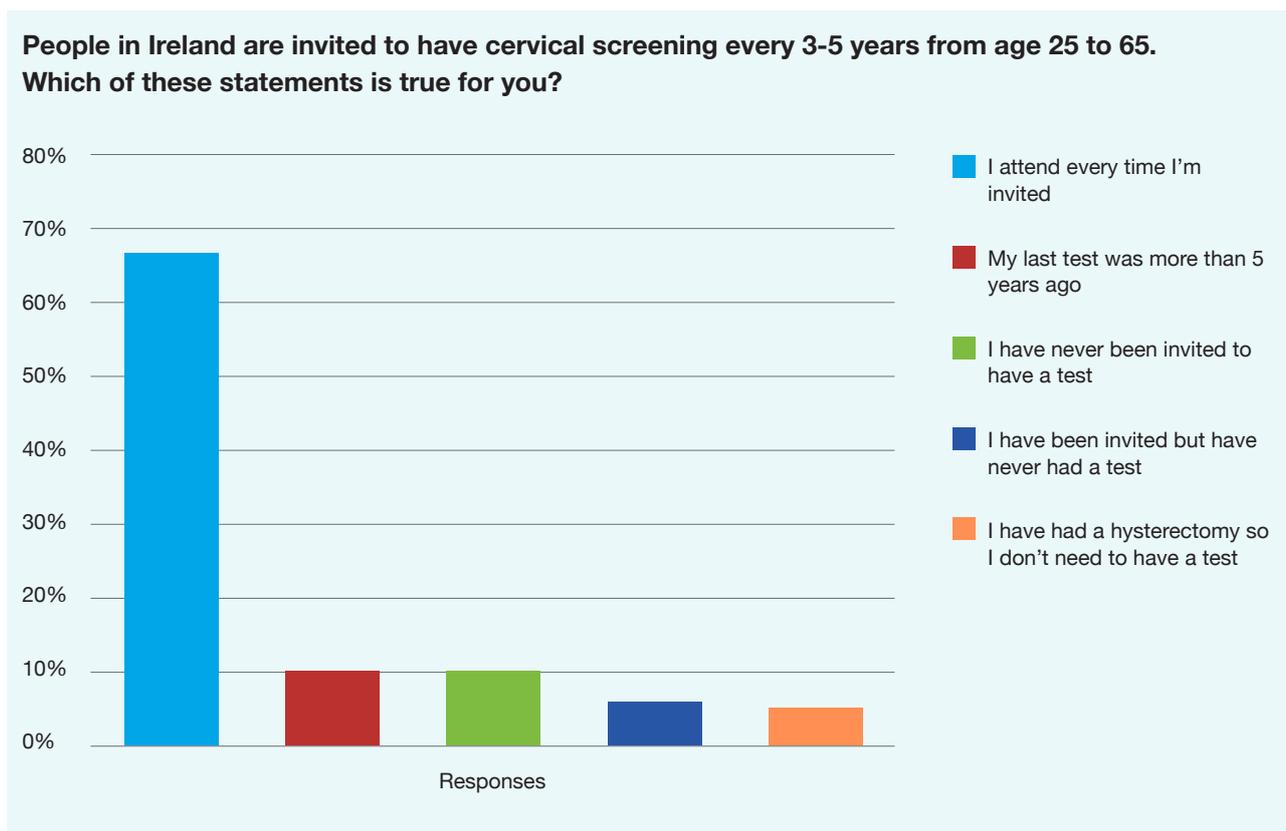


As would be expected almost 70% live in urban locations, compared to 30% who live in rural areas, with 65% of these living with a partner/family, 18% living alone and 14% in shared accommodation.

A surprising element was that almost 91% of respondents have third level education, compared with 42% in the general population (CSO 2016). Over 71% were employed, with almost 9% unemployed, 7.5% being full-time students and 6% unable to work, 25% hold a HSE medical card.

Smoking is a significant risk factor in cervical cancer therefore attention is needed in this area. Over 17% currently smoke with 41% being past smokers. This is in line with the Healthy Ireland survey which found the prevalence of smoking has dropped from 23% in 2015 to 17% in 2019.

Screening



Over 66.5% (two thirds) attend screening every time they are invited, which is somewhat concerning given that the national average for the general population is 80%.

Of more concern is the following: over 10% had their test more than five years ago, over 10% were never invited and over 6% were invited but did not attend. This 26% represents 106 people.

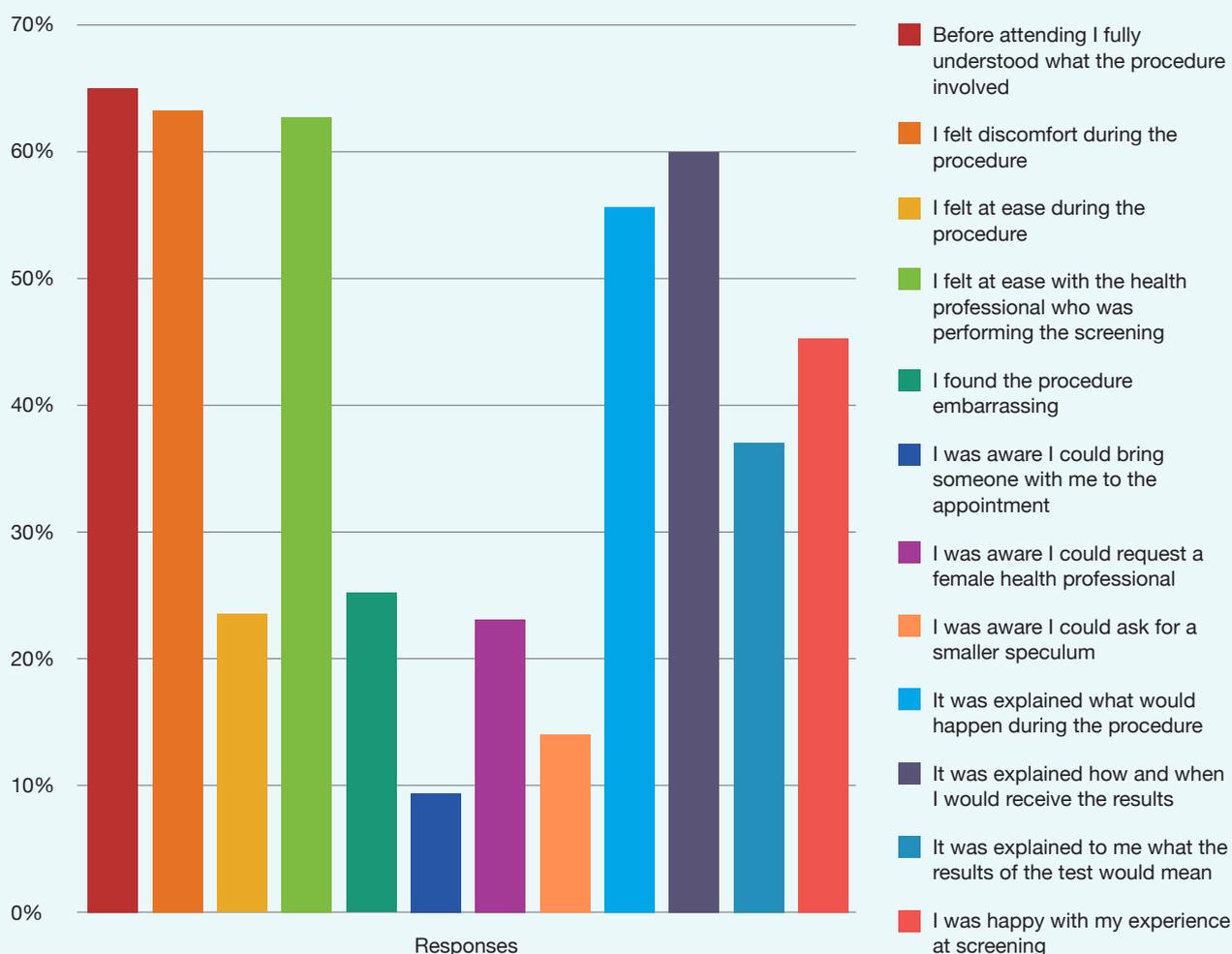
Almost 80% of people have their screening carried out by their GP or practice nurse. Many also stated in the comments that they attended the Well Woman Clinic in Dublin.

Respondents rated their overall experience of cervical screening at seven out of 10. Reasons given for this were: people fully understood the procedure; they felt at ease with the Healthcare Professional (HCP); the procedure and results were explained. Overall many were happy with their experience though as you will read below there were exceptions.

“The reason my experience was, and is, positive is because I’m out to my female GP and have been for some years. I chose her some years back because I knew she had other lesbian clients who were out to her. That gave me the confidence to come out to her and be at ease”.

“The first time I attended for screening in Ireland (I had a check in the UK - a painful experience) the nurse told me she would have to check if I should get a screen done, as I’m bisexual and have only had limited sexual experience with penises. On a follow up with the nurse I was told I did not need to get a cervical screen check. I still don’t know if this is true, as the information on the HSE website is not clear. These conversations have all been awkward as none of the professionals have known what should happen, and none of them have known the correct terminology to use (e.g. calling me a virgin although I have slept with women)”

Thinking about the last time you attended cervical screening: what statements below do you agree with? (please tick all those you agree with)



“It took a while to complete the procedure but this was handled with compassion and good humour”

However, two-thirds of respondents, i.e. 63% (212 people), felt discomfort during the procedure. When looking behind the numbers to understand their reasons, the following was offered:

“There is little knowledge or understanding in the medical profession about how painful it can be for lesbians who do not have penetrative sex, one medical practitioner even asked did I not use toys down there?”

“I found the experience incredibly painful. I didn’t know until I read this (survey) that I could ask for a smaller speculum. I have since ignored further invitations to be screened. It was horrible and I won’t be going back for all the tea in China!”

“At the end of the screening when I was signing the paperwork it asked for the ‘woman’s signature’ and not the patient. I am a trans man and it made me feel like I didn’t matter. I worry that if I had to get more tests done outside of the GP office I would be treated differently.”

“I felt a bit uncomfortable because the nurse assumed that I had a male partner and started speaking about condoms and other birth control methods, such as the pill. She was lovely but because she just launched into it I didn’t feel comfortable telling her I was with a woman.”

“My first experiences were awful. The doctor told me that because I was a lesbian I didn’t need a smear.”

There was a significant amount of commentary on the discomfort experienced by those who do not/have not had penetrative sex and those who have experienced sexual violence in the past. More awareness and appropriate responses by clinical staff are required in these circumstances. For example, *“It was among the worst and most traumatic experiences of my life, the lack of trauma informed care for survivors of sexual violence like myself is abysmal”*.

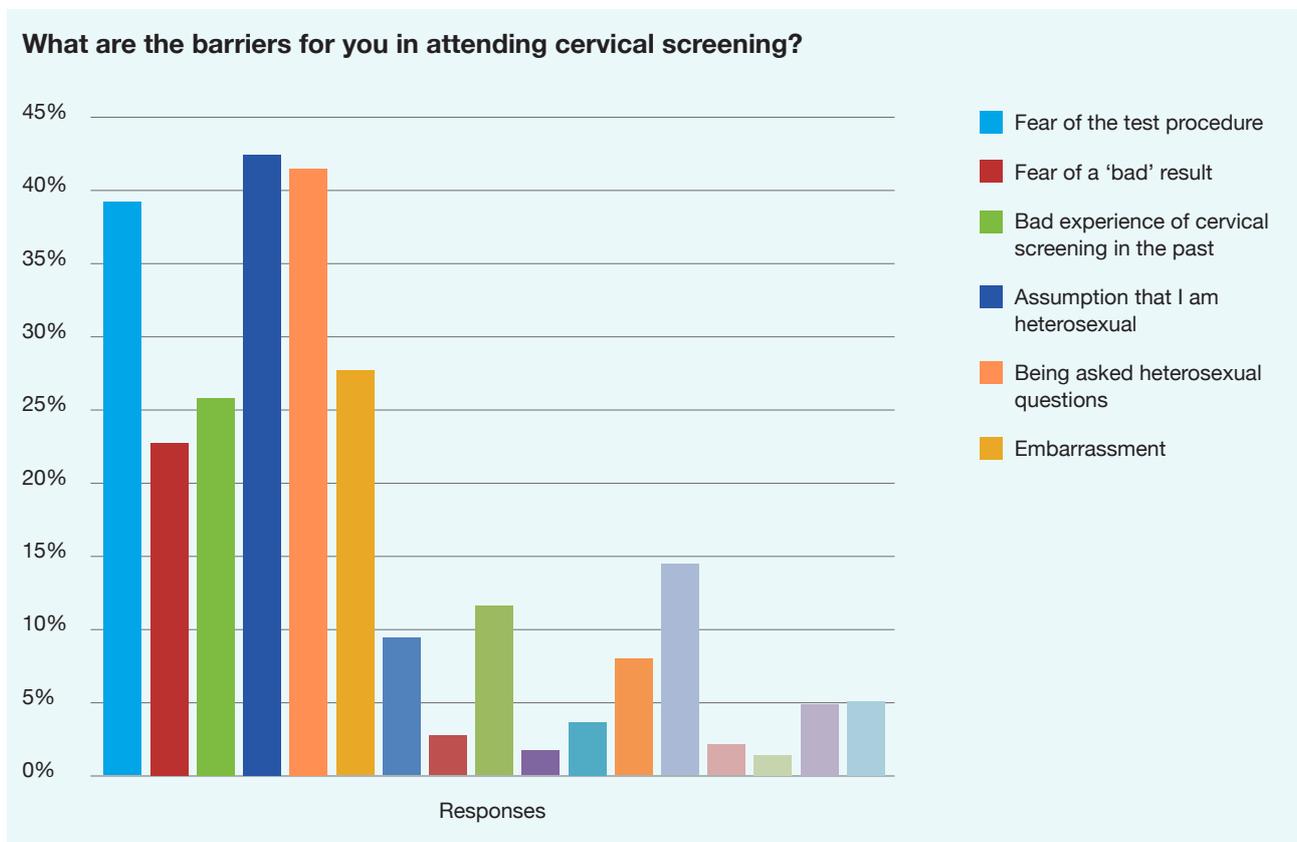
Experience of basic communication practices such as explaining what was happening during the procedure (55%), being informed about how and when the results of the test would be received (60%) and what the results of the test would mean (37%) is considered very low.

Barriers

When asked about the barriers for attending screening the following were identified as the top four barriers:

- ✓ Assumption that I am heterosexual (42.5%)
- ✓ Being asked heterosexual questions (41.5%)
- ✓ Fear of the test procedure (39.3%)
- ✓ Embarrassment (27.6%)

Over 62% do not state their gender/sexual identity when attending screening. Fourteen per cent of respondents have been told that they do not need to have cervical screening because of their gender identity/sexuality by a healthcare professional and 19% have been given this same misinformation from within the LGBT+ community.



What would encourage respondents to attend screening?

The top five priorities are:

- LGBT+ friendly practice (59.5%)
- Being able to book an appointment online (58.7%)
- Being sent a reminder by text (47.6%)
- Specialist LGBT+ Clinic (42.9%)
- More flexible GP surgery opening hours (41.8%).

What has encouraged them to attend in the past:

Early detection information, knowing risks, importance of screening, personal responsibility, GP, Public Health Nurse, screening invitation letter, friends and sister, fear of cancer, mother, reminders, personal stories, people with cervical cancer, reassurance, family or friends dying from cervical cancer, Jade Goody (English TV personality).

Attitudes and Knowledge of Cervical Screening

It would appear that overall there is a good understanding within the LGBT+ community of cervical cancer, screening, the risks involved and the HPV (Human Papilloma Virus).

However, in relation to knowing the symptoms of cervical cancer, there were a lot of respondents who said they were 'unsure', for example, almost 49% were unsure if post-menopausal bleeding was a concern. Similarly, knowledge about HPV and how this virus can be spread was not well understood by many who answered 'unsure'.

When asked where you would go to for information on cervical screening, the top three identified were:

- GP /Practice Nurse (44%)
- Online search (37%)
- HSE website (16%)

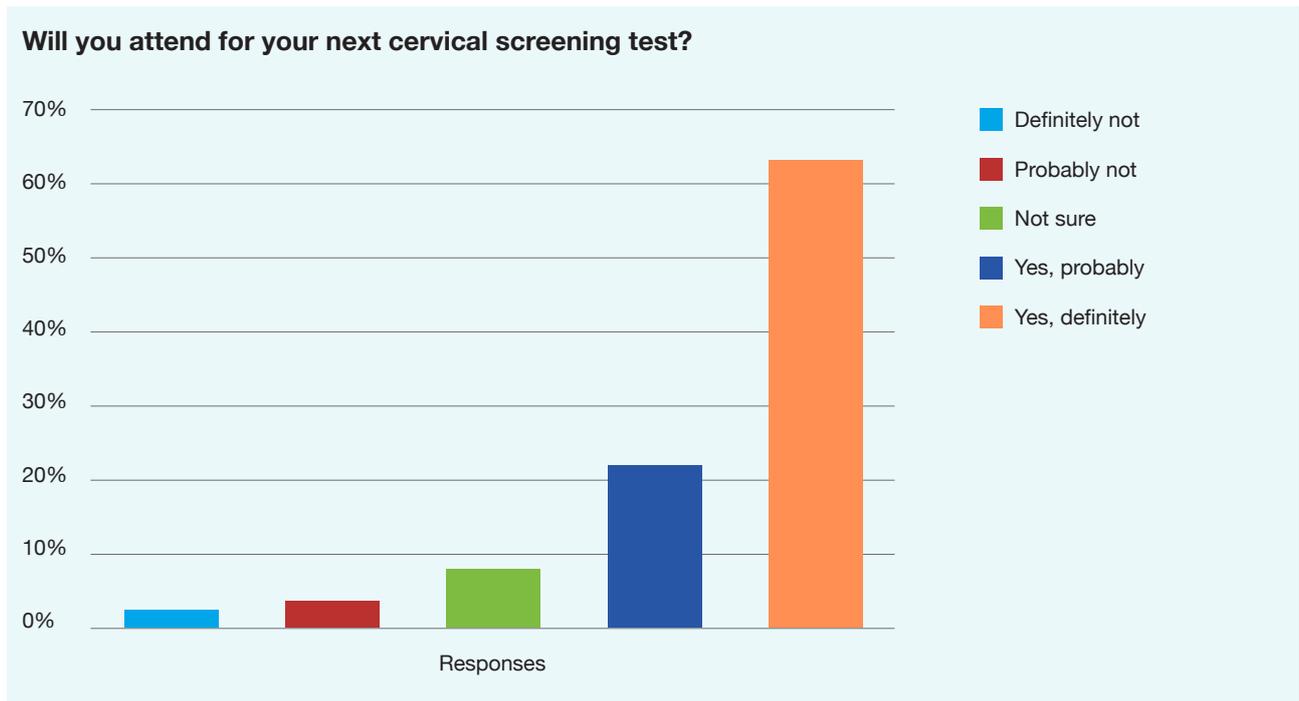
Followed closely by friends/family and information leaflets.

What additional information is needed? The following top three were identified:

- ✓ What symptoms you should look out for in between screenings
- ✓ The benefits of going for cervical screening
- ✓ The limitations of screening

Over 85% will definitely or probably attend their next cervical screening test, and over 90% would recommend screening to a friend/relative, all of which is very encouraging.

Finally, only 22% were not interested in home sampling, leaving a high number who were interested, open to it or unsure as of yet.



5. Stakeholder Interviews

The aim of the stakeholder interviews was to explore more deeply, from work professionals' perspectives, the findings that emerged from of the literature review and from the survey and the context for some of these findings.

Individual semi-structured interviews were held with four individuals – two healthcare practitioners (one urban and one rural), and two representatives of LGBT+ organisations (one urban and one rural). These are listed in Appendix I. Outline guide questions are also shown in Appendix II.

The main findings from the interviews with clinical practitioners are as follows:

Q: In your service what is your experience of engaging with the LGBT+ community?

Both healthcare practitioners mentioned that their engagement with LGBT+ people was informal and generally contact was made through sexual health clinics for STIs, regular smears or clients seeking advice. While there is no specific promotion of their services to the LGBT+ community⁹, they are aware that many of their clients are LGBT+ and they are welcome. Anecdotally, the practitioners believe that it is 'word of mouth' that encourages LGBT+ to attend their services. If clients have a good experience, they tend to tell others in their community.

In one rural area, it was felt that many lesbians enquired about the service, but did not take the next step and get screened. The practitioner in this rural area said there was a bigger uptake of screening by bisexual women compared to lesbians, who seemed fearful (of the procedure).

Both practitioners felt there was a lack of awareness of the need for screening among the trans community and also a lack of expertise on the clinical side in encouraging trans people into their services, which they feel can result in trans people being disaffected and excluded.

Q: The risk of cervical cancer among lesbians is frequently underestimated both by lesbians and healthcare professionals. Is this your understanding?

Both practices did not see 'risk' as a matter of concern for them and both see all clients (**those with a cervix**) as requiring a smear, regardless of who the sexual contact is with. One practitioner did feel that some lesbians don't think they need a smear and the other mentioned that lesbians who came to her practice feared the procedure including the use of the speculum. The procedure can often be uncomfortable. Both agreed that sensitive communication and reassurance was required by the sample taker.

⁹ The Well Woman Clinic did identify lesbian women on their website in the past.

Q: Awareness of barriers for LGBT+ people in accessing screening?

Both practitioners spoke strongly about the need to use language carefully, e.g. use the word partner, ask 'do you need contraception', ask open-ended questions. Both practitioners state that assumptions about a person's gender identity and sexual preferences should not be made. However, one suggested that their clinicians who are specifically trained are very comfortable talking about sexual activity, whereas this may be harder for local GPs.

The practitioner based in the rural location acknowledged that in Ireland everyone assumes you are heterosexual, but that one needs to treat people differently based on their needs; people are not all the same. The experience of attending for screening should be a positive one.

Both practitioners said they are very open to the LGBT+ community and open to doing more.

Training

The HSeLanD e-learning platform, which specifically has a module on 'LGBT+ Awareness & Inclusion Training: the basics', boasts over 100,000 active learners. It is available to health and social care staff at all levels across the statutory (HSE) and voluntary Health and Social Care sector agencies throughout the Republic of Ireland (Section 38 and 39). It is also available to third level Health and Social Care undergraduate students as well as agency professionals engaged by the HSE.

In addition, both LGBT Ireland and LINC both offer tailor made LGBT+ awareness raising workshops to many diverse groups in organisational settings.

The main findings from the two interviews with LGBT+ organisations are as follows:**Q: How do we address heteronormative questioning/assumptions at screening services?**

It was felt that healthcare professionals (HCP) are very well intended, but often not confident or trained in using a different language, e.g. different pronouns for identity. One LGBT+ organisation believes this requires behavioural change and practice on behalf of the HCP and from their experience a model that works uses the following framework: (a) first become aware (b) practice awareness and (c) put supports in place so that HCPs become confident using these practices.

Change needs to come from the top within the HSE and be promoted across local level, especially to GP practices. Both organisations mentioned their concerns about the language and assumptions being used by HCPs. One organisation noted that by including more LGBT+ people in various health settings it will build capacity within the system to engage and communicate with this community.

Q: Is it important to be 'out'?

The clinical environment needs to be overtly LGBT+ friendly, e.g. more posters, images of LGBT+ people and the use of more inclusive language. "You will feel welcome, safe and free to be out if you see yourself in these settings," said one respondent. In one rural location over 60 posters and flyers were given out to GPs and when they followed up to evaluate the impact most said they were too busy to put them up.

There were several examples given of older women in rural settings who have never been out to their GP. "They are closeted all their lives". It was also pointed out that healthcare service choice is very limited in rural areas and being out requires confidence and safety. It is important for your overall health and well-being to be out. "You should be able to receive a service comfortable in your own identity and feeling safe."

Q: How can the LGBT+ community encourage attendance at cervical screening?

Both urban and rural organisations said a ‘myth busting’ campaign is needed to emphasise the key messages across several health promotion campaigns in the community. There was a sense that the LGBT+ community underestimates some of the risks associated with sexual activity.

A specific LGBT+ sexual health campaign, including developing short video content, should be front and central and easily shared. It should specifically target young people as well as other cohorts within the community. It was suggested that real LGBT+ people in those videos and ensure those who don’t use social media are targeted in campaigns. Both organisations are open to working with CervicalCheck as partners.

Q: LGBT+ people do not need screening?

There were many examples given by LGBT+ organisations (and also noted throughout the literature and survey responses) that lesbians do not need a smear test if they were not having penetrative sex.

In some cases, which was specifically mentioned in a rural location, GPs have never offered a smear test, never had a conversation about screening, and there were instances where no invitation was received either from CervicalCheck. This person wondered if this was because she does not have children? Similar to the above point, it was suggested that LGBT+ people should be seen to promote screening.

As a context for this, it was pointed out that LGBT+ is not mentioned in the HSE National Service Plan 2020 and there is no LGBT+ Coordinator appointed at senior level in the National Social Inclusion Unit, unlike the NHS.

6. Focus Groups

Three focus groups were held during March 2021. These group meetings were held online via zoom and were hosted by LGBT+ organisations in Cork and Galway, and the third was held by TENI. These are listed in Appendix I. The main purpose of the focus groups was to deepen our conversation and understanding about some of the findings from the survey and the literature review, in both urban and rural settings. An outline of the topic guide questions is given in Appendix II. The sessions were hosted by the LGBT+ organisation and a number of facilitators were used to take smaller groups in breakout rooms to discuss in detail two questions each. All facilitators gave written feedback notes to the researcher.

The main findings are as follows:

Identity

There was a general sense that while it would be good to be out and be who you are, it is very hard to be out. Heterosexual assumptions are made about you even when you use the word 'partner' and in one case where someone was wearing an LGBT+ mask, no reference was made at all to their sexuality. It would be helpful if a question about identity was asked on the sign-in form initially, so that one can let HCP staff know in advance of how one would like to identify. This would make for a more comfortable environment for service users, and particularly for trans people.

Some people living in rural locations said "my identity never comes up – it's not important".

There were examples of many people being out to their healthcare provider and this is particularly more so the case in urban centres, where many reported their experience as being positive.

There was strong dismay for trans people surrounding the fact that many clinics only offer the option of 'Mrs, Miss, Ms or Mr' on forms. Additionally, in two cases, CervicalCheck invitation letters were sent to participants in their birth name, despite them both having legally changed their names.

Barriers

Inappropriate questioning

In the focus group discussions, some people gave examples of inappropriate questioning such as: "When I said partner, they assumed male. When I said I'm on the pill, they assumed birth control and asked me how many male sexual partners I've had?". Another woman said it was assumed she used sex toys and she was questioned about her relationship with her child's father.

Procedure can be uncomfortable

There was general agreement that the screening procedure was uncomfortable for most, but that it is a necessary procedure. This is in line with other studies (O'Dovovan *et al*) which stated that 'participants found smear tests unpleasant and those with adequate screening histories used coping strategies (e.g., breathing techniques) to reduce their discomfort. Most participants reported the benefits of competent sample takers in reducing women's anxiety'.

A barrier identified by trans people was gender dysphoria which many trans people often experience when it comes to any form of physical examination of their genitals.

Many participants across all groups did not know they could request a female sample taker and discuss the screening procedure, or that they could see the speculum and be told how it is used.

For some living in rural areas, several respondents mentioned 'not being believed by their GP (about being LGBT+)', 'experiencing regular heteronormative assumptions' and being requested to take a pregnancy test after stating they were not pregnant. 'One woman was advised to take a pregnancy test by the practice nurse, when she said "she didn't need one as she was a lesbian, the practice nurse became embarrassed and told her she didn't need to get too personal".

Across all focus groups there were examples where people had not received an invitation to screening. In some cases, they ignored this as they feared the procedure and in other cases they phoned in and made the appointment themselves.

In some cases, messages are being communicated by GPs and informally across the community that you don't really need screening if you're not having sex with men:

"I had a sexual health provider tell me there was a lot of testing I didn't need to get because my husband is a trans man and that because there's no insertion of a penis, there's no risk, which obviously isn't true for many things".

"I recently moved from the UK back home to Ireland. I was due my cervical screen which I have attended religiously since the age of 25. I'm now 33. My issue is I was told by my GP in Ireland that being a gay woman I did not need a cervical screen. I was really taken aback by the lack of knowledge. I am a healthcare professional myself so I know the importance of cervical screening and that your sexual orientation does not come into it, if you have a cervix you need a cervical screen. Who would be the best people to contact to raise this issue to ensure other people do not have the same experience I did? This is a LGBTQ issue, a woman's health issue and a public health issue, our GP's need educating".

What would help?

- We need more discussion about sexual health and sexual activity and this should include discussions on 'body shaming' as noted by the trans focus group.
- Promote the positive elements of screening for LGBT+ people by LGBT+ people, using multi-media short visual aids.
- Change the environment and the language and make the experience more accessible for trans and non-binary people as well.
- Let people know there are options, e.g. 'Would you like me to explain the steps as we go along? – 'Would you like to see the speculum'?
- Across all focus groups and in response to the survey, it was agreed that online booking of appointments with form filling upfront would assist many LGBT+ people to be out, to state their identity and to be more confident that they would be understood when they arrived for their appointment. This would make for a more comfortable experience for all concerned.
- Peer to peer support by the community was also mentioned as a practical action that the community could offer, in addition to campaigns in the community using short regular videos, which would remind people to attend.

- Having culturally competent medical providers was mentioned across much of the literature. For the LGBT+ community this means that the provider would not make heteronormative assumptions, ask irrelevant or uncomfortable questions and that the provider would be competent in understanding the importance of the correct use of pronouns and sexual identities/preferences. Ideally, the community would like to have LGBT+ sample takers/screenings available on certain days of the month. They believe this would certainly encourage attendance at screening.

60% said attending an LGBT+ practice or LGBT+ friendly clinical environment would help. What would this look like?

- Visibility i.e. LGBT+ information being on display would be the first step.
- Adequate LGBT+ awareness training for healthcare professionals.
- Outreach e.g. a mobile truck similar to BreastCheck: there was a suggestion of LINC and the Gay Project hosting a practice nurse in both community centres to offer screenings.
- Actively making patients aware that certain GPs are approachable and aware.
- Disseminate a list of LGBT+ friendly practices, develop a set of criteria / standardisation for listing LGBT+ friendly practices/HCPs including an emphasis on rural HCPs
- Promote LGBT+ screening on certain days – similar to that in bigger cities, e.g. New York.

A good example of an LGBT+ friendly practice in Galway was given:

A GP did a social media campaign targeted at attracting LGBT+ people to their service, saying they were an LGBT+ friendly practice and healthcare service, especially for trans people. This was also repeated on a flyer in the waiting room and by having a rainbow flag visible in the reception area.

7. Study Findings

In summary, the key findings from across the literature, survey, interviews and focus groups are the following:

- In our survey 88.9% of respondents were Irish, 70% live in urban areas, 72% were between the age of 25 and 45 and 91% had a third level qualification.
- Many LGBT+ people find the cervical screening service experience acceptable, over two-thirds attend screening regularly and are fairly knowledgeable about HPV, the risks involved, the screening procedure and cervical cancer.
- However, the national average uptake of screening is 80% whereas the LGBT+ community is below this figure at 66.5% and this is among a highly educated cohort.
- What was encouraging is that over 85% stated that they will or probably will attend their next screening test and 90% would recommend screening to others.
- In particular in this study, while LGBT+ people understood the importance and value of screening, it must be acknowledged that this study was conducted fully online and may have excluded more negative results from those most marginalised and who were unable to take part.

There were notable exceptions to these positive experiences. Key among these are:

Inappropriate attitudes, assumptions and language used by HCP

Inappropriate attitudes, language and incorrect assumptions make for a very uncomfortable experience and underpins the invisibility of LGBT+ people in cervical screening. This point is raised across many pieces of literature, all focus groups and acknowledged by all stakeholders.

Language and heteronormative¹⁰ assumptions were identified in the survey as being the biggest barrier to attending screening by all LGBT+ respondents.

There were many examples (given earlier) of inappropriate questioning and assumptions and sometimes this occurred in public spaces, such as reception areas in primary care settings.

All stakeholders agreed that LGBT+ people have specific needs and that these needs should be acknowledged. The LGBT+ community must also be empowered to communicate more with their HCP, as there can be a risk in not sharing information, e.g. trans people being incorrectly treated.

In addition, basic consultation practices, such as explaining the cervical screening procedure, being sensitive to service users' lived experiences, explaining how the result will be given and what it means, were absent in some cases.

¹⁰ Is the assumption or belief that heterosexuality is the default or normal mode of sexual orientation.

Messaging & misinformation

LGBT+ people want to see themselves in publicity campaigns in order to encourage the uptake of screening and raise awareness of other health-related matters such as smoking cessation, particularly given the high numbers who currently smoke or are past smokers.

Similarly, many clinical environments are not obviously LGBT+ friendly and while some HCPs believe they treat everyone the same, LGBT+ people have specific needs and in particular want to know they are welcome to attend screening as someone who identifies as LGBT+. There were two examples given where practices specifically targeted and welcomed LGBT+ people, but it was agreed that this does not happen generally.

There were many examples given in this study about receiving cervical screening misinformation; in particular that those who do not have penetrative sex or sex with men are less at risk. This is not true and while the practitioners in this study are well aware of this fact, clearly this is not understood by all HCP and GPs. International literature confirms a similar finding and states that many people have to insist on being screened which is also true in this study.

For some trans people, if they receive invitations in a different name to their current legal name, they feel further undermined.

Also, most people did not know they could bring a friend, ask for a female sample taker or discuss previous difficulties with cervical screening or their concerns about speculum insertion and opening. It is acknowledged that the size of speculum to be used in the procedure must be determined by clinical need but additional information and discussion during the consultation would make screening more acceptable.

In relation to knowledge of HPV, risk factors and symptoms, many LGBT+ people were unsure about the facts. Again, clear messages and information need to be communicated outwards by the National Screening Services.

Non-attendance/Over five years since attended

26% of respondents to the survey fall into the category of non-attendance (10% never invited, 6% invited but never attended and 10% over five years since attended), which is beyond the recommended repeat screening time period. This was confirmed through interviews and focus groups where some individuals gave clear examples of never receiving an invitation from CervicalCheck (and did not follow up themselves for an appointment as they had a fear of the procedure). Some had previous significant negative experiences, and would not go again. It is acknowledged that individuals who can participate in cervical screening can register themselves online or make an appointment to get a screening but many are unaware of this option. This finding requires further research.

Negative experiences

Many participants reported very negative experiences of the screening procedure itself, i.e. over 63% reported discomfort during the procedure, including finding it very painful, with some saying they would never go back again. Two issues that emerged in particular through the survey and through the focus groups was how uncomfortable the procedure was for those who do not engage in penetrative sex. The other issue which was highlighted was that for those who had experienced sexual violence in the past and trans people who experience 'gender dysphoria', the whole screening process can be frightening and very stressful.

What would help improve the uptake of screening?

- Being recommended to attend screening by your GP, HCP, own LGBT+ community. (Research confirms that people are four times more likely to get tested if recommended by a healthcare professional).
- Being encouraged through inclusive and targeted campaigning.
- An LGBT+ friendly clinic would strongly encourage attendance as ‘word of mouth’ is a key communication tool within the community. Practitioners and service users gave examples of such positive experiences. All stakeholders agreed more could be done to make clinics more LGBT+ friendly.
- Being given accurate messages about the benefits of screening and the risks of not screening.
- Support the community to become more comfortable with discussing sexual activity with their HCP, so that an accurate assessment of screening needs can be undertaken and the value of screening can be understood by LGBT+ people.

Knowledge of HPV and Risks

General knowledge of HPV and risks associated with getting cervical cancer was reasonably good among the LGBT+ people who responded to the study. However, there are several pieces of information in relation to HPV where many respondents were unsure. This would point to specific information which is not well understood, e.g. some symptoms of cervical cancer, such as post-menopausal bleeding or persistent lower back pain.

8. Recommendations for CervicalCheck

8.1 Training & Support for Sample Takers

- The National Screening Services (NSS) should promote LGBT+ training for sample takers including; LGBT+ Awareness & Inclusion Training: the basics (HSeLand), HSE social inclusion training, national and regional LGBT+ training provided by LGBT+ organisations.
- Provide good practice support to sample takers on the provision of services to the LGBT+ community, for example LGBT+ tools and resources, inclusive language, case studies, shared learning etc.
- Ensure sample takers recommend cervical screening to all LGBT+ people at every appropriate opportunity.
- Ensure good practice in consultation is followed each time in cervical screening and cover all the basic elements.
- Promote the e-learning module for sample takers on HPV screening.

8.2 Inclusion of LGBT+ community in cervical screening

- Include identity fields in the registration for CervicalCheck – and encourage sample takers to use identity fields in Primary Care registration systems. Use this data to monitor participation.
- Create a section on CervicalCheck website for the LGBT+ community and promote screening directly to the community using culturally appropriate images and language.
- Ensure the LGBT+ community is invited to participate in the NSS Patient and Public Partnership panel.
- Provide a point of contact in the National Screening Service for the LGBT+ community.

8.3 Communication with LGBT+ community

- Develop an LGBT+ communications campaign in relation to cervical screening – this should include a ‘registration call to action’.
- Explore the implementation of text message reminders in CervicalCheck.
- Encourage peer support in the LGBT+ community to encourage participation in cervical screening.
- LGBT+ service users should be given clear information about how to make a complaint and/or give feedback to CervicalCheck and/or HSE.

8.4 Partnership work

- Develop a partnership between NSS, the LGBT+ community and others, to oversee implementation of the recommendations in this report.
- Share the findings of this research to inform the development of national strategies e.g. Sexual Health Strategy, LGBT+ strategy etc.
- Explore the potential for LGBT+ cervical screening clinics.

8.5 Further research

- Carry out a needs assessment with HCPs in relation to the provision of cervical screening to the LGBT+ community.
- Examine further the reasons for non-attendance and for not returning to cervical screening by LGBT+ people.
- Similar studies in relation to LGBT+ participation should be considered across all relevant NSS programmes.

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APPENDIX I

LINC is the only community development organisation working exclusively with Lesbian and Bisexual women in the Republic of Ireland.

LINC aims to: Improve the quality of life, health and well-being of all women who identify as lesbian or bisexual in Ireland.



Our objectives are to:

- To build a safe, accessible and vibrant community centre (actual and virtual) for lesbians and bisexual (LB) women.
- To provide information and support for LB women and their families.
- To promote the mental, physical, emotional and sexual health of LB women.
- To inform and contribute to relevant policy development at local, regional and national level.
- To be a model of best practice rooted in feminist, social justice and community development principles.

Members of the Study Steering Group

Lynn Swinburne	NSS – Public Health and Health Promotion
Ciara Mulcahy	LINC Community Health Worker & Strategic Partner
Aoife Cooke	Community Representative (PPP)
Debbie Ramsbottom	CervicalCheck – Primary Care Co-ordinator
Dr Maria Power	Community Consultants

Stakeholder Interviews

Dr Shirley McQuaide	Well Woman Clinic Dublin
Orla Meenan	Rural Practice Nurse
Paula Fagan	LGBT Ireland
Bernardine Quinn	Dundalk Outcomers

Focus Groups

Cork	Hosted by LINC
Galway (West and Mid-West)	Hosted by Amach Galway
Transgender+	Hosted by TENI

APPENDIX II

Guide questions for clinical practitioners

Q1: In your service, what is your experience of engaging with the LGBT+ community?

Q2: Does your organisation carry out any specific initiatives to engage/welcome the LGBT+ community?

Q3: The risk of cervical cancer among lesbians is frequently underestimated and unrecognised by both lesbians (19%) and healthcare professionals (15%). Are you aware of this and what could be done to change it? (In our survey 21% of women who have sex with women underestimate the risk of contracting cervical cancer and consider themselves at lower risk of cervical cancer than heterosexual women).

Q4: In your opinion are healthcare workers aware of the specific barriers for LGBT+ community in accessing screening services?

- For example, our study shows that 41% of the respondents identified heteronormative assumptions (and 40% identified heteronormative questions) and being rendered invisible in clinical settings (page 21/22) as significant barriers.
 - Is this your experience/understanding and what could be done to address this problem?
- In many practices, an ‘equal treatment approach’ and not adopting ‘special measures’ (page 16/17) ends up alienating marginalising LGBT+ people.
 - What can be done about this understanding?
- Worried Well? Many people attend but are afraid or embarrassed by the procedure. Why is this? What can be done to help?

Q5: Are you aware of the following guidance documents which were recently published

https://lgbt.ie/wp-content/uploads/2020/11/Guide_for_Providing_Care_for_Lesbian_Gay_and_Bisexual_Patients_in_Primary_Care_Quick_Reference_Guide.pdf

<https://www.gendergp.com/review-of-gp-guide-for-trans-care-in-ireland/>

Q6: What recommendations would you have for CervicalCheck in promoting screening services to the LGBT+ community?

Guide questions for LGBT+ stakeholders

Q1. What is the impact of heteronormative questioning/assumptions in your interactions with screening services? How do we address it?

Q2. Almost 63% are not out to their healthcare professional. How can we encourage those who would like to tell their gender/sexual identity to their HCP? What would help?

Q3. 59% in our survey identified an LGBT+ friendly GP practice environment would encourage them to attend screening – what would this look like? Give details?

Q4. Also, being encouraged to attend by my community (28%) – how might we encourage greater participation in partnership? What does that look like?

Q5. If people have been told they don't need screening (19% by community), what's the context of those interactions?

Q6. What is your experience of LGBT+ engagement in healthcare? What more could be done in partnership?

Topic Guide

Focus Groups (up to 12 participants per group)

Welcome everyone and contextualise how we will work on Zoom today and time-slots. (Use humour to relax everyone into the session) – Chair/each org (Maria will talk through before then) **(5 mins)** ✓ Maria introduce the facilitators.

The discussion will start with a brief overview of the study, purpose and work to date. **(Lynn 5 mins)**
Slide 1- 4.

Key findings from the survey and literature review will be highlighted – these inform the questions we would like to explore with you today **(Maria, 5 mins)** Slide 5 - 9.

Chair to put participants into break-out rooms (4 into each with a facilitator). Each group has two different questions to focus on (in-depth questions with sub-parts) – facilitator teases out question, ensures participation and probing to gain greater insights, deeper understanding and examples. Facilitator writes up summary feedback on main points/responses given. **(30 mins in break-out rooms)**.

See questions on separate page.

Chair gives time notice and brings facilitators, note-takers and participants back.

(All summary notes sent to Maria later).

All back in the big group: Ask one overall general question re preferences/what strategies/action would improve the screening experience/other and how do we get more LGBT+ people to attend? (15 mins)

Finish with: study dates, where to go to get more information and a nice closing video? (5 mins)

Thank everyone and close.

Questions for focus groups

Each facilitator to take two questions each per breakout room.

Introduce with first names, explain your role and the need for engaged participation.

Q1: In our survey when asked – ‘When you attend for cervical screening, do you state your gender identity/sexuality?’

63% did not state their identity – Why do you think that is? Is it important to do so? What would assist you to do so? What difference would this make to primary care interaction?

Q2: Some of the significant barriers identified by LGBT+ people when attending screening were:

43% of the respondents identified heteronormative assumptions

42% being asked heterosexual questions

Being rendered invisible in clinical settings (page 21/22).

Is this your experience? Describe.

What could be done to address this problem?

Q3: When asked – ‘what are the barriers for you in attending cervical screening?’

Many people say they attend but are:

‘1. Embarrassed 2. Are fearful of the test, and 3. Have had a bad experience of cervical screening in the past.’

Why is this?

Q4: There can be misinformation about the risk of cervical cancer for LGBT+ people. Some LGBT+ community members and some healthcare professionals think LGBT+ people are at lower risk.

What can the LGBT+ community and CervicalCheck do about this?

Q5: When asked – ‘What would encourage you to attend cervical screening?’

60% said LGBT+ friendly GP practice environment –

What would this look like? Give details?

Q6: When asked – ‘What would encourage you to attend cervical screening?’

29% said ‘being encouraged to attend by my community’ – How might we do this together in partnership with CervicalCheck? What would this look like?

What other strategies would encourage community members to attend screening?

Question for large group – what strategies/actions can be introduced to make screening services more accessible and LGBT+ friendly? How can we encourage greater uptake?

Prompts:

Ask those in the small groups to build on each other’s responses and develop ideas with detail (we will be taking notes)

Ask why questions, what would be the benefits, what actions would they like to see taken, how?

