

**Trans and non-binary people’s experiences of accessing and attending cervical screening in the North of England**

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# Abstract

Transgender people face discrimination and inequality in various areas of life, including within healthcare. A key health disparity is the limited uptake of cervical screening compared to cisgender women. A scoping review highlighted the paucity of research in this area. Therefore, the aim of this thesis was to undertake an in-depth, qualitative study to explore transgender men and non-binary peoples (trans+) experiences of cervical screening to develop recommendations to improve experiences of this service.

15 trans+ people shared their experiences of cervical screening in a semi-structured interview (10), or an online, asynchronous focus group (5) conducted between November 2022-March 2023. Participants were recruited through purposive and snowball sampling using various social media and LGBTQ+ newsletters. Inclusion criteria were being trans+, aged 25 or over, having or previously having a cervix, and living in the North of England. Participants were aged between 25-45, and the majority (13/15) had a disability, and were mostly (13/15) white British.

Data were analysed using reflexive thematic analysis, through which four themes were developed that explore various barriers and facilitators to attending cervical screening. For example, in cases where health professionals were not sensitive and respectful, trans+ participants reported more negative experiences, such as heightened physical pain and gender dysphoria, compared with then health professionals were knowledgeable and reassuring. Further, trans+ people shared complexities of deciding whether to attend cervical screening. These decisions were shaped by previous experiences of health services, concerns about heightened gender dysphoria or pain, and the potential emotional impacts of cervical screening.

The findings had multiple implications for practice, policy and future research to improve cervical screening for trans+ people. For example, trans+ people value being given choice in cervical screening, and shared what they would like health professionals to know about their identities and health needs.

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# Glossary of abbreviations

For ease of reference, I have provided a list of the abbreviations used within this thesis. Abbreviations are also written in full the first time that they appear in each chapter.

AFAB: assigned female at birth

AMAB: assigned male at birth

CCS: cervical cancer screening

GP: general practitioner

HCP: healthcare professionals

NHS: national health system

TMNB: trans men and non-binary people

SMW: sexual minority women

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# Chapter 1: Introduction and Background

## 1.1 Introduction

Gender diverse people face inequalities in health and healthcare, one of which is cervical screening. In this thesis I explore trans+ peoples experiences of accessing and attending cervical screening. This chapter introduces key elements of this study, including why this research is necessary and defining key terms used throughout this thesis. I provide context for this thesis, such as the importance of cervical screening in maintaining health, and experiences of trans+ people in health services and wider society, and the North-South divide. I also discuss existing literature within these areas to begin to highlight knowledge gaps regarding cervical screening for trans and non-binary people. Throughout the following text, I also draw attention to the way in which the use of qualitative approach within this thesis will enable me to bridge the knowledge gaps identified in the scoping review presented in Chapter 2.

## 1.2 Transgender health

Inequality and discrimination of transgender people is evident in all areas of life, including medicine and healthcare (Faye, 2022). Trans+ people often face adversity within health care despite the legal duty of all health and social care organisations to provide equal treatment under the Equality Act 2010 (Bachmann and Gooch, 2018a). It is often erroneously assumed that transgender health is only relevant in trans-specific health services such as gender-affirming care, however transgender people face issues within all areas of medicine and health care whether or not their trans status is directly relevant (Vincent, 2018b). The term transgender refers to people who identify as a gender other than their sex assigned at birth, whereas, a cisgender person is someone who identifies with their sex assigned at birth (Stonewall, 2017). Some trans+ identities fall within the gender binary, which refers to the system of individuals being classified into two categories: man or woman (Vincent, 2020). However, this system is oversimplified and outdated as evidenced by the existence of intersex and non-binary individuals (Vincent, 2020). Binary-oriented trans identities are trans men, which refers to people assigned female at birth (AFAB) who identify as male, and trans women, someone who was assigned male at birth (AMAB) and identifies as a woman (Stonewall, 2017). Identities which go beyond the gender binary can be referred to under the umbrella term non-binary, which means they do not identify as male or female (Stonewall, 2017; Vincent, 2020). Non-binary genders include genderqueer, agender and bigender, among many others which all have subtle differences (Vincent, 2019, 2020). This thesis is concerned with transmasculine people, which refers to those who were AFAB but identify as a non-female gender, however for levity the terms “transmasculine, trans and non-binary, or TMNB” will be used throughout this thesis to refer to the gender identities explained above.

The way that healthcare has traditionally been set-up has been accused of ignoring the existence of trans people, which can make accessing health care difficult for trans+ people (Pearce, 2018; Vincent, 2018). For example, most health research focuses on cisgender people, meaning trans people are excluded from the research that provides an evidence base for health care, rendering them invisible within medicine and health (Pearce, 2018; Vincent, 2018a). Furthermore, in medical schools, trans+ health care is seen as a specialty only necessary for those who will work in gender affirming care, when in fact trans+ people have the right to good health care in all areas (Vincent, 2018b). This lack of inclusive education about trans+ people and their health has contributed to poor health outcomes among trans+ populations. This includes a higher prevalence of mental health issues and substance abuse, and a lower uptake of screening services such as cervical cancer screening (CCS) (Pearce, 2018; Datta and Kumar, 2022). Not attending CCS is a significant risk factor for cervical cancer as it places people at risk of missing early cervical cell changes, meaning the limited uptake of screening among trans men and non-binary people (TMNB) places them at a higher risk of developing cervical cancer (Reisner *et al.*, 2018; Dhillon *et al.*, 2020). The research conducted therefore aims to explore TMNB experiences of CCS to understand barriers and facilitators to accessing and attending screening, and to inform modifications to improve them.

Discrimination and unequal treatment can be overt from healthcare professionals (HCP) who harbour negative attitudes towards trans+ people, who can be rude or aggressive to trans+ patients or refuse to treat them (Shires *et al.*, 2019a; Carlström, Ek and Gabrielsson, 2021), or due to cisnormativity, which refers to the way society privileges cisgender people (Stonewall, 2017). Cisnormativity is dominant in medicine, such as the lack of training on providing appropriate health care for trans+ people or having medical textbooks which only show traditionally male and female bodies, thus creating a poor understanding about providing care for trans+ people (Vincent, 2019). This impacts health care in a variety of ways, for example, trans+ patients are often the first trans+ patients that HCPs have encountered so many HCPS ask inappropriate questions out of curiosity or expect the patient to educate them on trans+ issues which can cause discomfort (Vincent, 2019). Additionally, HCPs often make incorrect assumptions, such as assuming that all trans+ people desire to transition medically using gender affirming surgery and hormone therapy, rather than being aware that all transitions are different and finish at different stages, with some trans+ people only desiring to transition socially (Heng *et al.*, 2018; Pearce, 2018). This is especially relevant to non-binary people who are often assumed to want to medically transition to the “opposite” sex, rather than having a discussion of which affirming care options they actually desire, or having to present as a binary gender in order to receive gender-affirming care due to health practitioners who gatekeep access to certain treatments (Vincent, 2020). This shows that the widespread discrimination from health care providers in the UK, which can be both intentional and unintentional, impacts trans peoples’ health (Bachmann and Gooch, 2018b).

The rise in anti-trans media and legislation in recent years has also impacted trans+ peoples experiences of everyday life, including healthcare (Dhanani and Totton, 2023; Webberley, 2024). For example, there has been a significant increase in media articles which negatively target trans+ people. The impact of seeing anti-trans news consistently has had a significant emotional impact on trans+ people and has created further fears around receiving appropriate healthcare, experiencing harassment or violence, and has increased avoidance of healthcare (Dhanani and Totton, 2023). The LGBT in Britain Health Report (Bachmann and Gooch, 2018b) found that 32% of trans+ people reported having experienced unequal treatment within the National Health System (NHS) and 62% of trans+ people reported NHS staff lacking understanding about trans-specific health needs. These experiences can lead to trans+ people mistrusting health professionals and/or avoiding health care due to experienced or expected discrimination (Bachmann and Gooch, 2018b; Pearce, 2018).

There has been an increase in research about trans+ people in recent years, however there is a limited body of research which centers trans+ health experiences. Despite the multitude of trans+ health disparities which have been identified, health research often neglects to include trans+ people, or conflates LGBTQ+ and trans+ identities which ignores the nuance of trans+ experiences (Vincent, 2018b). Further, trans+ health research tends to be quantitative and thus there is a limited understanding of trans+ health experiences in trans+ people’s own words. This has contributed to the perception of trans+ people as a homogenous group with little variation in experiences, despite the vast variation which exists. Highlighting the diversity among trans+ peoples experiences of health care may help to challenge ideas surrounding trans+ people being a homogenous group. The use of intersectional theory regarding trans+ health experiences has the opportunity to disrupt the tendency of health professionals treating trans+ people in the same manner despite vast differences in experiences and preferences for health care, including but not limited to gender affirming care. Therefore, the focus on diversity in trans+ health experiences is a key element of this thesis in order to improve understandings of trans+ experiences of health care and personal, cultural or societal influences of these to allow the development of recommendations which center trans+ peoples lived experiences of health services.

This thesis takes a social constructionist approach, which is explored in more detail in Chapter Three: Methodology. Social constructionism views the world as constructed through social norms, interaction, discourse and other processes within the societies that we live in (Braun and Clarke, 2013). This thesis is concerned with the contexts in which participants’ experiences are produced and potential reasons surrounding this. Considerations of these are especially important in health research, as developing policy and practice to improve health experiences only works when underlying issues are understood, and underlying issues can only be addressed when people are asked about them (Holloway and Freshwater, 2007). Exploring trans+ experiences of cervical screening from trans+ people’s own perspectives, in their own words, and with as much detail as participants are open to providing has the potential to develop a more comprehensive understanding of these experiences, including underlying factors, links between factors and to place importance on elements which trans+ people themselves feel are the most prominent. Therefore, a social constructionist approach to trans+ health research is important as it recognises the social, historical, cultural and temporal contexts and how these interact to influence trans+ experiences of health services.

## 1.3 Cervical cancer

One area where trans+ health inequality is particularly apparent is CCS as trans+ people are 60% less likely to attend this service (Kiran, 2019). Cervical cancer is the cancer of the cervix, which is the organ that connects the vagina to the womb (Cancer Research UK, 2020). Symptoms include unusual vaginal bleeding or discharge, pain during sex, and pelvic pain, however many people with cervical cancer do not experience symptoms (Cancer Research UK, 2020). Every day in the UK, nine people are diagnosed with cervical cancer, and two lives are lost due to cervical cancer (Jo’s Trust, 2019). Cervical cancer screening is the best protection against developing the condition (Jo’s Trust, 2019).

Cervical cancer develops when abnormal cells in the lining of the cervix grow undeterred and form a tumour (Cancer Research UK, 2020). Abnormal cell changes are caused by human papillomavirus (HPV) when the infection is persistent, or is a high risk strain such as HPV type 16 or 18, which cause around 70% of all cervical cancer (Crosbie *et al.*, 2013). The HPV vaccination programme, which aims to protect people from the transmission of HPV, has significantly reduced mortality since its introduction in 2008 (Crosbie *et al.*, 2013). However, the vaccine can only protect against 70-80% of cervical cancer, meaning that screening is recommended regardless of HPV vaccination status (Crosbie *et al.*, 2013; Harb *et al.*, 2019).

Trans+ people may be at a higher risk of developing cervical cancer due to the lower uptake of screening meaning that abnormal cell changes may be missed (Kiran, 2019). Additionally, trans+ people report higher rates of smoking and sexual violence than their cisgender counterparts, which are both factors that increase the likelihood of acquiring HPV, meaning cervical screening is especially important for these groups (Gatos, 2018). Thus reducing disparities in screening uptake is vital to ensure that trans+ people are not placed at an unnecessary risk of developing cervical cancer.

## 1.4 Cervical cancer screening

Cervical cancer can be prevented through regular screening to detect early changes in cervical cells, which can be treated to prevent development of cancer (Public Health England, 2021). Additionally, regular screening can reduce the disease progression as early detection means treatment can begin promptly (Crosbie *et al.*, 2013; Cancer Research UK, 2020). Early treatment limits the growth of cancer cells into the surrounding areas, thus reducing the risk of cancer spreading (Burns *et al.*, 2007). This reduces both the risk of mortality and ongoing physical and psychological issues suffered by cancer survivors who receive treatment too late, such as bladder and bowel dysfunction or dyspareunia which can negatively affect their quality of life (Burns *et al.*, 2007). This highlights the importance of CCS in saving the lives and improving the quality of life of cervical cancer patients (Burns *et al.*, 2007).

The CCS programme in the UK offers screening for people with a cervix aged 25-64 years old, or after 64 if the person has never attended screening or if their last test showed abnormal changes (Public Health England, 2021). The CCS procedure is called a Papanicolaou test and involves using a speculum to gently separate the vaginal walls to allow providers to visually examine the cervix, and use a small brush to collect cervical cells (Public Health England, 2021). This sample is tested for HPV and checked for abnormal cell changes under a microscope (Public Health England, 2021). If abnormal changes are detected, the individual is invited for a colposcopy to confirm whether the changes are cancerous or pre-cancerous and are given appropriate treatment (World Health Organisation, 2021).

## 1.5 Cervical cancer screening for transmasculine people

CCS is often viewed as a women’s procedure, however it is an important procedure for many genders as transmasculine people who retain a cervix should also attend screening (Dhillon *et al.*, 2020; Datta and Kumar, 2022). This includes a large number of TMNB, who often retain a cervix either due to their own preferences, or the long waiting lists and limited access to gender-affirming surgeries (James *et al.*, 2016; Pearce, 2018).

However, there are barriers to CCS for trans+ people which has resulted in a lower rate of attendance to screening among TMNB (Dhillon *et al.*, 2020; Plummer *et al.*, 2021). These include systematic barriers, for example, all people registered as female with their GP automatically receive an invitation every three years, however trans men who are registered as male do not receive this invitation despite potentially needing this service (Public Health England, 2021). Additionally, GP systems only offer binary gender classifications – male or female – which means gender diverse people have to select one of these, so not all TMNB receive an invitation to screening (Public Health England, 2021). This also means that some cisgender women who do not require screening, for example due to having a hysterectomy, as well as trans women and non-binary people who are registered as female and do not have a cervix are also sent invitations despite this not being necessary (Dhillon *et al.*, 2020). Thus, the current invitation system can be a barrier to accessing screening.

Trans-specific barriers to screening also relate to experiences within the screening appointment. For example, TMNB often experience a higher level of pain during screening due to testosterone use which causes vaginal atrophy; the thinning and drying of vaginal walls which can increase pain during penetration (Berner, *et al.*, 2021a). Additionally, transmasculine people may experience gender dysphoria due to the focus on their genitalia and may feel heightened embarrassment at HCPs seeing this area of their body (Connolly, Hughes and Berner, 2020; Weyers *et al.*, 2021). Furthermore, TMNB are less likely to provide adequate cervical samples, for example transmasculine people are more likely to provide a sample which has too many red blood cells for testing to be completed, which may mean they need to repeat the potentially distressing procedure (Reisner, Deutsch, *et al.*, 2018). This highlights the need for trans+ people to be given equal but not identical care, as they should also be able to access screening but have different needs to cisgender women (Caulfield *et al.*, 2016).

## 1.6 North-South Divide in Health

The North-South divide refers to the disparity in health and wealth between those who live in the North of England and those who live in the South (Kontopantelis *et al.*, 2018). Despite the North-South divide being well evidenced for many years, the gap in health disparities is widening over time (Bambra, Barr and Milne, 2014; Alhassan and Castelli, 2020; Corris *et al.*, 2020). There are many inequities when comparing health indicators in the North to the South (Alhassan and Castelli, 2020). For example, people living in the North have both a lower life expectancy and healthy life expectancy (Bambra *et al.*, 2023). Further, people in the North are consistently less healthy than those in the South, including when comparing this within social classes and gender (Copeland, Kasim and Bambra, 2015). These worse health outcomes are related to the higher mean levels of deprivation in the North, however deprived areas in the North have worse health outcomes than similarly deprived areas in the South (Bambra, Barr and Milne, 2014). For example, for almost all types of cancer, including cervical cancer, the risk of death is higher and more likely to happen sooner in deprived areas (Kontopantelis *et al.*, 2018). The research consensus suggests that the North-South divide is driven by economic and political reasons such as inequalities in social determinants of health (Bambra *et al.*, 2023), the quality of availability and access to health services (Copeland, Kasim and Bambra, 2015) and the unequal government spending between the North and the South (Alhassan and Castelli, 2020).

There is also a North-South divide between both incidence and mortality of cancer (Rashid *et al.*, 2024). For example, those living in Northern cities including Manchester, Liverpool and Newcastle, and in coastal areas, were at greater risk of dying of cancer than those in wealthier London boroughs including Westminster, Kensington and Chelsea (Rashid *et al.*, 2024). Further, when considering the age-standardised mortality rate from cancer by local authority, the highest 12 rates were in local authorities in the North, compared with 11/12 of the lowest rates being in the South, with one in the midlands (Harker, 2024). The highest incidence of cancer is in the North East, for example the North East had the highest rates of lung cancer registrations in 2017 at 107.9 people per 100’000 people, compared with 65.2 per 100’000 in the South East (Office for National Statistics, 2019). There were also regional differences in cancer incidence rates within oesophagus, stomach, skin and cervical cancer (Office for National Statistics, 2019). For example, the highest rates of cervical cancer occurred in the North West (defined as Cheshire, Cumbria, Greater Manchester, Lancashire and Merseyside) and the lowest in the East (defined as Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk) (Office for National Statistics, 2019). The widest inequities also seem to be among cancers where risk can be reduced through lifestyle changes such as weight loss and smoking cessation, or for those where screening is available (Rashid *et al.*, 2024). Access to health services including screening programmes vary between urban, rural and coastal areas, which leads to disparities in early detection of cancer and thus disparities in outcomes (Scott and Hoskin, 2024), which highlights a need to consider variation between areas in the North, and thus this thesis considers differences in experiences of trans+ people accessing cervical cancer in cities vs rural areas. Further, the existence of a North-South divide in incidence of cancers which can be prevented through screening highlights a clear need for further research into cancer screening in the North in order to understand reasons why this may be lower, and to develop recommendations to improve future uptake.

## 1.7 Summary of the background chapter

This chapter has presented context for this thesis and key issues in relation to cervical screening for trans+ people in the North of England, and defined key terms used throughout this thesis. Further, this chapter begins to explore the rationale for this research, which is continued in the following chapter. Currently, there is a paucity of qualitative research exploring TMNB experiences of CCS. This means that barriers to cervical screening have been identified, however there is a limited understanding of how these impact trans+ peoples experiences of screening, and how they interact to contribute to positive or negative experiences. As above, conducting qualitative research underpinned by social constructionism in trans+ health topics also allows trans+ people to share what is most important to them, in their own words, which allows for the development of potential improvements to patient experiences based on what trans+ people themselves feel is a priority. There is a further lack of research within the UK, where the small number of projects that have been published are quantitative and conducted in the South of England, as evidenced within the literature review (Chapter 2). To address the issues identified above, the aim of this PhD study was to explore trans+ peoples experiences of, and attitudes towards, accessing and attending CCS in the North of England qualitatively and with influences from social constructionism, intersectional theory, queer sociology and queer methods, and which draws on a person-centered care approach to improve experiences of this service. The following chapter presents the scoping review undertaken to examine the current research in this area in order to understand what is currently known and to identify gaps in the literature.

# Chapter 2 – Literature Review

The scoping review was published in the Journal of Clinical Nursing (Rivers et al 2024) and is presented in Appendix 1. This chapter provides further detail on methods and results.

## 2.1 Introduction

Inequality and discrimination of transgender people is evident in all areas of life, including medicine and healthcare (Faye 2022). The term transgender refers to people who identify as a gender other than their sex assigned at birth, whereas a cisgender person is someone who identifies with their sex assigned at birth (Stonewall 2017)[[1]](#footnote-1). This scoping review synthesises published research in this area to show what is currently known about trans men and nonbinary peoples (TMNB) experiences of cervical cancer screening (CCS).

Globally, trans+ people have low rates of access to health care due to issues such as violence, legal barriers and discrimination. For example, most countries do not legally recognise transgender identities, which contributes to exclusion and marginalisation (World Health Organisation 2022). The Equality Act 2010 states the legal duty of all health and social care organisations in the UK to provide equal treatment; however, trans+ people often face adversity within these services (Bachmann and Gooch 2018). The LGBT in Britain Health Report (Bachmann and Gooch 2018) drawing on a survey of 5375 LGBT people, including 752 trans+ people, found that 32% of trans+ people had experienced unequal treatment within the National Health Service (NHS), including inappropriate curiosity and discriminatory remarks from health care staff. These experiences can lead to trans+ people mistrusting health professionals or avoiding health care due to experienced or expected discrimination (Pearce 2018; Bachmann and Gooch 2018). Additionally, 62% of trans+ people reported NHS staff lacked understanding about trans-specific health needs (Bachmann and Gooch 2018). This may be due to the lack of education on trans health care, which is seen as a specialty area only necessary for those who will work in gender affirming care, even though trans+ people have the right to good health care in all areas (Vincent, 2018b).

Furthermore, 40% of trans+ people said they had experienced difficulties accessing health care due to their trans status (Bachmann and Gooch 2018). For example, a high proportion of TMNB report gender-identity discrimination in health care, which can deter them from seeking health care in the future (Eiduson et al. 2021). TMNB who have had negative experiences with health care professionals (HCP), or heard of such stories from others, can anticipate further mistreatment, which can lead to delaying treatment (Gomez et al. 2021).

Gendered health settings can also cause discomfort among TMNB, for example the gendered language within health services may feel like a constant stressor, leading to heightened dysphoria (Gomez et al. 2021). Many health care settings and providers intentionally or unintentionally treat TMNB as abnormal or ‘other’ due to the extent of cisnormativity in health care. This means TMNB must constantly combat assumptions about their bodies, their gender and their sexuality, which can decrease willingness to return for necessary health care (Eiduson et al. 2021). Furthermore, non-binary individuals are often treated as a binary gender, especially in situations or conditions that are usually associated with a specific gender. For example, in a recent study, a non-binary participant with endometriosis was perceived as a woman, i.e. in language used in relation to the condition (Eiduson et al. 2021). This highlights the need to consider how health services can be supported to be more inclusive and meet the needs of binary and non-binary trans people.

A health service where this is particularly apparent is CCS as trans+ people are less likely to attend this service than their cisgender counterparts. A small number of United States (US)/ Canada research has aimed to quantify this, for example a Canadian study reported that trans+ people are 60% less likely to attend this service (Kiran 2019). Cervical cancer symptoms include unusual vaginal bleeding or discharge, pain during sex, and pelvic pain; however, many people with cervical cancer do not experience symptoms (Cancer Research UK 2020). Not attending CCS places people at risk of missing early cervical cell changes, meaning the limited uptake of screening among TMNB places them at a higher risk of developing cervical cancer (Reisner et al., 2018; Dhillon et al., 2020).

The CCS programme in the United Kingdom (UK) offers screening for people with a cervix aged 25-64 years old, or after age 64 if the person has never attended screening or if their last test showed abnormal changes (Public Health England 2021). Cervical cancer is caused by abnormal cell changes due to the human papillomavirus (HPV). If left untreated, the abnormal cell changes may develop into a tumor (Cancer Research UK 2020). The HPV vaccination programme, which aims to protect people from the transmission of HPV, has significantly reduced mortality since its introduction in 2008 (Crosbie et al. 2013). However, the vaccine can only protect against 70-80% of cervical cancer, meaning that screening is recommended regardless of HPV vaccination status (Crosbie et al. 2013; Harb et al. 2019).

Regular cervical screening saves lives. Screening detects early changes in cervical cells, which can then be treated to prevent development of cancer (Public Health England 2021). Additionally, screening can halt disease progression as early detection means treatment can begin sooner (Crosbie et al. 2013; Cancer Research UK 2020), reducing the risk of cancer spreading (Burns et al. 2007), and thus resulting in better patient outcomes. This reduces the risk of mortality and ongoing physical and psychological issues suffered by cancer survivors who receive treatment later, such as bladder and bowel dysfunction or dyspareunia, which can affect their quality of life (Burns et al. 2007).

Additional risk factors for acquiring HPV and developing cervical cancer include smoking and sexual violence, which trans+ people report higher rates of (Gatos 2018); therefore, it is imperative to improve the uptake of CCS among TMNB. However, increasing the uptake requires understanding TMNB experiences of cervical screening to develop and implement changes to improve patient experiences of CCS and ultimately make CCS more accessible to TMNB.

## 2.2 Aims and Objectives

The aim of this scoping review is to synthesise research on this topic to provide an overall understanding of TMNB experiences of cervical screening and to identify implications to improve cervical screening experiences and uptake in the future, using the following objectives:

* To explore what is currently known about TMNB experiences of accessing and attending cervical cancer screening.
* To understand factors which affect experiences and uptake of cervical screening among TMNB and to provide recommendations for future improvements.

## 2.3 Methods

### 2.3.1 Design

I carried out a scoping review to explore the existing literature on TMNB experiences with CCS, following the framework from Arksey and O’Malley (2005) as this is the most frequently used framework in scoping reviews (Pham *et al.*, 2014). A scoping review was selected as they are often used in health research on topics with little published literature in order to demonstrate what is known and to identify gaps in the literature (Pham *et al.*, 2014).

### 2.3.2 Search strategy

The population, exposure, outcome (PEO) acronym was used to develop the search strategy for this review (Bettany-Saltikov and McSherry, 2012). The PEO framework is widely used across nursing and health research to guide the development of research questions and the accumulation of appropriate key words (Bettany-Saltikov and McSherry, 2012). For this review, the population is TMNB, the exposure is CCS, and the outcome is experiences. To ensure that the search was comprehensive, the key words, which included transgender, cervical screening and experiences, were exploded, as presented in Appendix 2, to include all potential synonyms. An initial scoping review was undertaken in 2021, and an updated search was undertaken between 23/06/23 and 03/07/23. The search strategy involved using key terms and Boolean operators in order to identify all potential literature (Arksey and O’Malley, 2005). The following databases were searched due to their extensive literature on health research: Medline via PubMed, Web of Science, Scopus and CINAHL.

Initial scoping searches, which involved using key terms to search the University Library, Google Scholar and the above databases, revealed the paucity of literature in this area so supplementary methods were used to ensure maximum exposure to relevant literature (Aveyard, Payne and Preston, 2016). In addition to database searching, Google Scholar, grey literature and citation searches were conducted to increase the number of papers identified for the review. I searched for grey literature using the Bielefeld Academic Search Engine (BASE) which is one of the most comprehensive grey literature search engines. I identified 154 papers using this search strategy, and 112 remained once duplicates were removed.

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| **Inclusion criteria** | **Exclusion criteria** |
| Literature that focuses on trans+ peoples experiences of cervical screening | Literature that focuses on rates of screening or disparities between adequate samples |
| Any method and date range | Included sexual minority women (SMW) but did not specify whether findings were from SMW or trans+ participants |
| Written in English | Written in a language other than English |
| Empirical research articles | No geographical criteria were used |

### 2.3.3 Search Outcome

The titles and abstracts of each paper were screened for inclusion against the eligibility criteria, which led to 81 papers being excluded for non-relevance. Papers were included if they focused on the experiences of TMNB in CCS and written in English. Additionally, papers were excluded if they focused on rates of screening, disparities between taking adequate cervical swabs, or did not disaggregate findings between sexual minority women (SMW) and TMNB. Qualitative, quantitative and mixed-methods research papers were included in this review as excluding papers based on methodology would exclude relevant publications on TMNB experiences, which is already limited. No publication year exclusion criteria were used as the earliest paper on this topic was published in 2008. I then read the remaining articles and scrutinized them against the eligibility criteria, resulting in 8 papers being excluded. Therefore, a total of 23 papers were included in this review. A flow chart of this process is presented in Appendix 3.

### 2.3.4 Data abstraction and synthesis

Key information from the 23 papers was extracted into a data charting sheet (as presented in Appendix 4), which is a record of the key characteristics and findings of papers (Tricco *et al.*, 2017). Charting is used in a scoping review to gather information required to show what has been researched in the area and demonstrate the results rather than finding an answer to a research question, as done in a systematic review (Tricco *et al.*, 2017).

The charted data were then analysed thematically following guidelines outlined in Braun and Clarke, (2022). This involved creating codes which included similar experiences, such as “gender dysphoria” and “fear of discrimination”, which were then grouped together to create three themes which represent the findings of the literature review.

* Theme 1 – Physical, psychological, and emotional distress
* Theme 2 - Experiences due to the healthcare system
* Theme 3 - Experiences due to practitioners’ behaviours and attitudes

## 2.4 Critical analysis

Although scoping reviews do not usually include a critical analysis (Pham *et al.*, 2014), I felt it was important to reflect on some elements of the included papers to provide transparency and important context surrounding the literature that is included. This critical analysis was guided by Critical Appraisal Skills Programme (CASP) checklists, which provide guidance to help researchers think critically about research (Critical Appraisal Skills Programme, 2018).

All 23 studies were conducted in the Global North: 13 in the USA, four in the UK, two in Australia and one in Aotearoa, New Zealand. In the three review papers, all (Gatos 2018) or the majority of studies reviewed were conducted in the US, with one from France, Canada and Italy (Connolly, Hughes, and Berner 2020), and one from Canada and the UK (Dhillon et al. 2020). The majority of participants in each study were aged between 18-30 years, non-Hispanic White, TMNB patients recruited from specialist LGBTQ+ services. This means that there is limited diversity of participants within the studies included in this review.

Of the 23 papers, 17 were research studies, 11 of which were qualitative (Agénor et al., 2016; Bernstein et al., 2017; Carroll et al., 2023; Dutton et al., 2008; Gibson et al., 2021; Johnson et al., 2016, 2020; Kerr et al., 2020; McDowell et al., 2017; Peitzmeier et al., 2017, 2019), two mixed-methods (Berner, Connolly, et al., 2021a; Potter et al., 2015) and four quantitative (Harb et al., 2019; Roznovjak et al., 2023; Seay et al., 2017; Shires et al., 2019). Three of the papers were literature review articles (Connolly et al., 2020; Dhillon et al., 2020; Gatos, 2018), two were recorded conference presentations (Berner et al., 2021c; Berner, Connolly, et al., 2021b) and one was a conference abstract (Semlyen and Kunasegaran, 2016). Additionally, two research articles, (Bernstein et al., 2017; McDowell et al., 2017), were doctoral dissertations. Sample sizes ranged from 7 participants (Semlyen and Kunasegaran, 2016) to 196 participants (Kerr, Fisher and Jones, 2020). Qualitative methods included interviews and focus groups, and each quantitative paper used a survey method. There was a wide variety of analysis methods, from thematic analysis to descriptive statistical analysis, and thus the following review includes a wide variety of research design, data collection and analysis. No papers were excluded based on quality and thus the following review includes only studies of high-quality research and trustworthiness.

Some participant experiences discussed in the selected papers were omitted due to the lack of clarity about who had shared them. For example, Johnson et al., (2016) did not separate SGM women’s experiences from the experiences of trans+ patients throughout the paper so some discussions had to be ignored as it was difficult to ascertain whether they were provided by women or TMNB. In addition to this, a paper was excluded because the researcher did not separate any experiences between TMNB and SGM women, and instead opted to call all participants “women” throughout the paper.

Furthermore, research on provider perspectives required providers to be interested in research about trans+ health. This means that providers with negative feelings towards TMNB may not have been responded to calls for participants, and thus are not included in this research. Therefore, willingness of health care providers to screen TMNB may be skewed as those who harbour negativity towards trans+ people may not be involved in the research. Additionally, data may be skewed to be positive as all research including providers was undertaken in the US and Australia (Agénor *et al.*, 2016; Bernstein *et al.*, 2017; Peitzmeier *et al.*, 2019; Shires *et al.*, 2019a; Gibson *et al.*, 2021), both of which have relatively good levels of tolerance towards trans people (Flores *et al.*, 2021). Despite the recent rise in anti-trans media and legislation in the US, when considering the global context, the US continues to have relatively good treatment of trans+ people. For example, at least nine countries have national laws criminalizing forms of gender expression that target transgender and gender nonconforming people (Human Rights Watch, 2023). This includes Indonesia, which criminalises LGBTQ+ people with a maximum penalty of eight years imprisonment and/or 100 lashes, with evidence of the law being enforced in recent years (Human Dignity Trust, 2025). Further, LGBT+ advocacy groups are not allowed to formally register in Indonesia, and trans+ people are regularly met with violence, discrimination and arbitrary arrest (Human Dignity Trust, 2025). Therefore, it is clear that the US continues to have relatively good treatment of trans+ people and thus only including literature from the US, and Australia, will positively skew trans+ experiences of accessing health care when compared to countries where being trans+ itself is criminalised.

Additionally, of the five papers which included providers, three (Agénor et al., 2016; Bernstein et al., 2017; Peitzmeier et al., 2019) used the same 17 providers recruited from a trans-specialist clinic, which limits the diversity of providers discussed in this review. Therefore, studies on provider perspectives in countries with laws prohibiting transgender rights or the legal existence of trans+ people may have different results on the numbers of providers willing to screen TMNB.

Additionally, most participants were recruited from specialist trans+ or LGBTQ+ health services, organisations or events, which means that TMNB who are not registered at these services or who do not engage with LGBTQ+ organisations or events may be excluded from the review. Although some researchers made efforts to recruit a diverse group of participants, such as Peitzmeier et al., (2019), who aimed to recruit older trans+ patients and trans people of colour by slowing the recruitment process to provide more time for harder to reach groups to respond, rather than recruiting the people who respond first, the overwhelming majority of participants included in this review were white and young (aged under 30 years) and therefore the experiences of older adults or people of colour may not be represented.

Finally, despite having no geographical exclusion criteria within my selection strategy, all research took place in the Global North which means TMNB people from other countries and cultures are not represented. TMNB living in countries with less tolerance towards LGBTQ+ people may experience adversity when accessing or trying to access cervical cancer screening or may be denied this altogether. Therefore, this review is limited to the experiences of young, white TMNB living in developed countries.

## 2.5 Findings

Through thematic analysis as described above, three themes were identified which capture trans+ experiences and perceptions of cervical screening: Theme 1 – Emotional and psychological distress; Theme 2 - Experiences of the healthcare system; Theme 3 - Health care providers attitudes and behaviours towards TMNB. The findings are discussed within the themes below.

### 2.5.1 Theme 1–Emotional and psychological distress

Patients and providers consistently reported that TMNB experience physical and psychological distress, discomfort and anxiety when attending, or considering attending CCS (Agénor et al., 2016; Dhillon et al., 2020). TMNB are often aware of the importance of screening for health; however, the emotional distress can be so severe that a significant proportion of TMNB avoid CCS (Dutton et al., 2008). For example, 55% of TMNB patients in Australia reported avoiding CCS due to anticipating the procedure to be emotionally traumatic (Kerr et al., 2020). This is caused by multiple, often interlacing, factors, which are outlined below.

#### Physical pain

The majority of TMNB patients worry about experiencing physical pain during the screening procedure (Berner et al., 2021a). Physical pain is frequently reported across all people who attend CCS, and can lead to patients delaying or avoiding screening due to the fear of this pain (Connolly, Hughes and Berner, 2020). However the addition of androgen therapy, such as testosterone which is often used by TMNB to affirm their gender identity, can worsen the pain felt by TMNB (Connolly, Hughes and Berner, 2020). This is because testosterone use can lead to vaginal atrophy, which refers to the thinning, drying and inflammation of the vaginal walls, thus making the screening procedure more painful (Connolly, Hughes and Berner, 2020). Additionally, androgen therapy is associated with less adequate samples being collected, which means that TMNB patients often have to undergo multiple painful and distressing procedures in order to collect an adequate sample (Connolly, Hughes and Berner, 2020).

#### A history of sexual trauma

CCS can be distressing for anyone with sexual trauma; however, globally, there is a higher rate of sexual trauma among TMNB than cisgender women (Gibson et al., 2021); therefore, it is important to understand how this affects CCS in order to improve uptake and experiences among TMNB. TMNB patients with sexual trauma often reported negative experiences including distress, a loss of control and PTSD-like symptoms during CCS (Bernstein et al., 2017). Some TMNB also shared that sexual trauma prevented them from attending screening due to fear surrounding the invasive nature of the procedure (Carroll et al., 2023). Additionally, many participants discussed worries of being touched by a stranger or being ignored if they needed the procedure to stop (Bernstein et al., 2017). In one study, the idea of penetration was extremely distressing to a participant, so the use of the speculum meant they were not able to access screening (Johnson et al., 2020). This participant had scheduled multiple CCS appointments; however, had cancelled them due to fear and anxiety (Johnson et al., 2020).

#### Heightened gender dysphoria before, during and after cervical cancer screening

Gender dysphoria, which refers to the distress caused by the incongruence between gender identity and sex assigned at birth (Johnson et al., 2016), was consistently discussed across the literature and was reported as one of the primary reasons for delaying or avoiding cervical screening (Carroll et al., 2023; Roznovjak et al., 2023). Some TMNB experience gender dysphoria throughout their everyday lives; however, it can be exacerbated by CCS due to the focus on genitalia (Berner, Connolly, et al., 2021a; Johnson et al., 2016). One participant stated that the focus on their genitals during screening left them feeling like they were pre-transition as they felt as dysphoric as they did before receiving gender-affirming care (Peitzmeier et al., 2017). Additionally, TMNB patients can feel uncomfortable with the practitioner seeing their genitalia as this means the practitioner is aware they do not have a traditionally male body, which may not be the case in their everyday lives (Peitzmeier et al., 2017). Some participants also reported that the physical contact during CCS heightens their dysphoria (Carroll et al., 2023; Dutton et al., 2008). As a result, TMNB report feeling dysphoric, vulnerable and exposed during screening (Peitzmeier et al., 2017). Gender dysphoria can also be triggered by correspondence about CCS, including being sent an invitation, booking an appointment, or discussing the need to access CCS (Berner, Connolly, et al., 2021a, 2021b; Dhillon et al., 2020). This is due to CCS being seen as a ‘woman's exam’, so such correspondence reminds the patient that they have anatomy that is incongruent with their gender (Dhillon et al., 2020). Many TMNB also report feeling worried about being outed by the screening invitation, which refers to other people discovering their trans status, due to seeing that they require CCS (Berner, Connolly, et al., 2021b). Heightened gender dysphoria can continue to be experienced following the procedure (Bernstein et al., 2017). For example, CCS may lead to disturbing aftereffects such as vaginal bleeding (Dhillon et al., 2020; Potter et al., 2015). One participant reported experiencing severe pain during the procedure and bleeding for two days following, which caused menstrual dysphoria, trauma, and avoidance of future CSS (Bernstein et al., 2017). This participant had called for the procedure to stop; however, the practitioner had ignored this request. Additionally, the thought of developing cervical cancer can be distressing for many TMNB (Connolly et al., 2020). One participant stated that having cervical cancer would lead to dysphoria so intense that it ‘would kill me as much as the disease would kill me’ (Peitzmeier et al., 2017: p2144). This means that TMNB must navigate the risks of discomfort caused by CCS, along with the risks of developing cervical cancer and the distress this would cause (Connolly et al., 2020; Peitzmeier et al., 2017). However, dysphoria is not a homogenous experience among TMNB during CCS. Some participants do not experience dysphoria during CCS (Connolly et al., 2020), while others report that their dysphoria during CCS has reduced as they progress further into their transition (Bernstein et al., 2017; Peitzmeier et al., 2017). Furthermore, Peitzmeier et al. (2017) p2140 suggests that people who identify as more masculine, such as transgender men or masculine-leaning nonbinary people, may experience more severe gender dysphoria as compared with people who identify further away from the masculine end of the spectrum (Peitzmeier et al., 2017). This is further evidenced in Kerr et al. (2020) which found that trans men in Australia were much less likely to attend screening than gender diverse people. Additionally, Peitzmeier et al. (2017) suggests that gender dysphoria may be less severe in people who are able to view CCS as gender neutral, thus suggesting the extent of gender dysphoria can be influenced by where both identity and perception of the procedure are placed on a masculine-feminine spectrum. Some participants report that they have become more comfortable in their bodies and no longer feel dysphoria during CCS (Bernstein et al., 2017). One participant stated that a bad experience during CCS would not cause gender dysphoria or affect their self-esteem as they are affirmed and accepted by themselves and other people in their life (Bernstein et al., 2017). However, a participant who was not accepted by their family discussed feeling intense dysphoria during screening as they feared that the practitioner would have a similar reaction (Bernstein et al., 2017). Therefore, the extent of gender dysphoria experienced during CCS may be affected by how the participant views their own body, and how their body is viewed by others (Bernstein et al., 2017; Kerr et al., 2020).

### 2.5.2 Theme 2–Experiences of the healthcare system

Many systematic barriers to CCS for TMNB were identified (Bernstein et al., 2017; Gibson et al., 2021). This theme explores the impact of the way the health system can affect TMNB experiences of screening, for example, often TMNB who are registered as male on health records in the UK, US and Aotearoa do not get invited to CCS because current systems do not recognise that TMNB may require CCS. This, among other issues, which are outlined below, has resulted in trans patients reporting feelings of discomfort and distrust within health services.

#### Feeling ignored and invisible within healthcare

Globally, TMNB have often been excluded from CCS policy, provision and research, resulting in some TMNB feeling ignored within CCS (Agénor et al., 2016; Gibson et al., 2021). For example, many TMNB participants discussed their frustration at the lack of research and guidelines around CCS in the US (Agénor et al., 2016). Contrastingly, the Australian national CCS program recently began using gender-inclusive language and recommending screening for all people with a cervix (Kerr et al., 2020). At the time of publishing, 44.6% of participants in an Australian study had never been recommended screening but this change was expected to improve the uptake of CCS across Australia (Kerr et al., 2020). The lack of inclusion of TMNB in discussions of CCS means that some TMNB patients are unaware that they are at risk of cervical cancer, or may feel like their health is at risk and seen as less important than that of cisgender women (Agénor et al., 2016). Some participants navigated worries about their gynaecological health by regularly attending screening, such as one man who stated that regular screening helps him to feel safe and healthy (Agénor et al., 2016). However, due to the uncomfortable nature of CCS, the lack of awareness of the need for TMNB to access screening, and the unwillingness of some providers to screen TMNB, many TMNB do not attend screening (Agénor et al., 2016; Berner, Connolly, et al., 2021b). Furthermore, many TMNB report distrust in the healthcare system (Bernstein et al., 2017). For example, health services and health insurance companies may only cover CCS for people registered as female on their health records (Bernstein et al., 2017; Connolly et al., 2020). This means that many TMNB patients are unable to change their gender marker as they would no longer be able to access CCS; therefore, the inability to align their legal gender with their gender identity is a direct result of the healthcare system (Bernstein et al., 2017). Because of this, many TMNB view healthcare as an impediment to their transition (Peitzmeier et al., 2017). Some health services and insurance companies state that people registered as male on their health records cannot access pap smears due to ‘gender incongruence’, referring to screening only being needed among women, which ignores that women are not the only people with cervixes (Bernstein et al., 2017). Additionally, in the UK, labs often fail to process cervical samples from TMNB due to having a male name on the form (Berner, Connolly, et al., 2021b). This can be reiterated by providers reporting the results, as evidenced by one trans+ man in the US who was told ‘This is, can't be for you. You don't have a vagina.’ (Gibson et al., 2021). This was stated in front of the waiting room, causing the patient to feel extremely uncomfortable, and he never received his results (Gibson et al., 2021).

#### Perception of CCS as a ‘woman's procedure’

Historically, CCS has been seen as a woman's procedure, despite its importance for everyone with a cervix (Kerr et al., 2020). Levels of comfort often depend on whether providers affirm their patient's gender identity during screening, and whether patients are able to view CCS as gender neutral (Peitzmeier et al., 2017). Health services can (un)intentionally reinforce the feminisation of the procedure in many ways (Peitzmeier et al., 2017). For example, many health services refer to CCS as a ‘well women's exam’, which excludes TMNB (Peitzmeier et al., 2017), and resources such as leaflets and pamphlets are aimed at cisgender women, which reinforce that they are not open to other identities (Dhillon et al., 2020). The gendered nature of many health settings can be uncomfortable and dysphoria inducing, which can make accessing healthcare as a TMNB difficult. This is especially true when seeking sexual/ reproductive healthcare such as CCS. Some TMNB patients report avoiding appointments at gynaecology clinics due to feeling unwelcome as a result of the non-inclusive environment (Harb et al., 2019). TMNB patients report feeling more comfortable when they are not the only TMNB in the waiting room. For example, at trans-specific health clinics, or clinics which set aside appointment blocks specifically for trans people (Dhillon et al., 2020; Johnson et al., 2020). Many TMNB reported feeling uncomfortable or misunderstood when making CCS appointments by providers and receptionists who discourage or turn away TMNB from attending CCS due to their gender identity and the misconception that CCS is for women only (Berner, Connolly, et al., 2021a, 2021b). Additionally, TMNB may feel uncomfortable when signing non-inclusive intake forms, such as only having ‘male’ or ‘female’ options on gender questions (Dutton et al., 2008). This reminds TMNB patients that healthcare services are not inclusive (Peitzmeier et al., 2017).

### 2.5.3 Theme 3 –Healthcare provider attitudes and behaviours towards TMNB

TMNB have consistently reported that the attitudes and behaviours of healthcare providers can greatly impact their experiences of CCS. For example, in Aotearoa, 30% of those who delayed screening did so due to worries of how they would be treated by HCPs (Carroll et al., 2023). This theme discusses how HCPs can impact TMNB experiences of CCS, both positively and negatively.

#### Discrimination by healthcare providers

Due to worries about adverse experiences with healthcare providers or services, many TMNB opt to access trans-specialist clinics for CCS in the UK and US (Berner, Connolly, et al., 2021a; Dhillon et al., 2020; Peitzmeier et al., 2017). There is a lower uptake of CCS among patients who are not connected to LGBTQ+ competent clinics (Seay et al., 2017). TMNB report feeling more comfortable attending CCS at a trans-specialist health clinic as the providers have a better understanding and experience, meaning trans people feel less anxious about stigma or discrimination (Berner et al., 2021c). For example, all those who reported a positive experience of CCS in a study by Harb et al. (2019) were screened in LGBTQ+ clinics or by a provider who specialised in trans healthcare. Furthermore, a service for TMNB to access CCS was piloted in the UK in which 12/20 patients who were screened there said they would not have accessed screening if the clinic had not existed (Berner, Suchak, et al., 2021). However, many TMNB patients have reported positive experiences with non-specialist providers who carry out the procedure with patience and understanding, and provide good aftercare (Berner, Connolly, et al., 2021a). In contrast, some TMNB report negative experiences caused by a lack of sensitivity towards, and education on, trans issues among HCPs (Carroll et al., 2023; Peitzmeier et al., 2017). For example, some participants reported being referred to by their deadname [[2]](#footnote-2)in a waiting room (Dhillon et al., 2020), which can exacerbate the distress already felt by being the only masculine-presenting person in a room full of cis women. Further, some healthcare workers take a long time and require multiple conversations with TMNB patients about their identities, to accept and acknowledge different gender identities, which can create concern among patients that requesting CCS would result in them being viewed as less masculine (Berner, Connolly, et al., 2021a). Previous negative experiences with medical professionals, both within and outside of CCS creates distrust among HCPs and results in TMNB anticipating further negative experiences in CCS (Johnson et al., 2020; Potter et al., 2015). A higher level of discrimination both in healthcare and everyday life is associated with avoiding health services due to a fear of how providers will treat them (Johnson et al., 2020). This can cause worry about disclosing their trans identity to HCPs due to concerns of how they will react (Dutton et al., 2008), which may affect whether patients feel comfortable requesting a CCS appointment (Johnson et al., 2020). For example, one participant changes their gender expression to present as female to avoid transphobia when attending screening (Johnson et al., 2020). Therefore, HCPs behaviours and attitudes towards trans people and their bodies play a key role in influencing whether patients will attend screening, and whether they have a positive, neutral or negative experience (Gatos, 2018; Kerr et al., 2020). Many TMNB patients reported that providers had ignored their calls for the screening exam to stop due to discomfort or distress, which they described as a violation or compared it to rape (Peitzmeier et al., 2019). Additionally, some participants felt unable to tell the practitioner to stop, and instead carried on with the procedure despite discomfort (Peitzmeier et al., 2019). This highlights that the experience of CCS can be made significantly worse if health professionals do not listen to the needs or requests of their patients.

#### Provider's capability and willingness of providing care to trans people

Despite 85% of CCS providers in a US study stating that they would be willing to screen transgender patients, many TMNB patients report difficulties finding HCPs who do so (Shires et al., 2019). Several patients have been turned away from screening by practitioners who said they had no experience with TMNB patients (Bernstein et al., 2017). One TMNB patient reported negative experiences with overtly transphobic HCPs, and worried CCS would provide practitioners another opportunity to attack them (Berner, Connolly, et al., 2021a). This is a significant issue as practitioners play an important role in CCS access; for example, 38% of TMNB participants in an Australian study did not access CCS due to an inability to find a provider they felt comfortable with (Kerr et al., 2020). Furthermore, Shires et al. (2019) found that only 40% of the providers in their US based study had screened a transgender patient in the past 5 years, suggesting that despite willingness to screen trans patients, many providers have no experience. As discussed in Gatos (2018), this is potentially due to practitioners being willing to screen TMNB but not feeling like they had enough knowledge to do so appropriately. This can create further worry among trans patients who, as above, would prefer a practitioner with experience caring for trans+ patients (Dhillon et al., 2020; Peitzmeier et al., 2017). TMNB report positive experiences of CCS when their providers show respect and sensitivity towards their gender identity (Dhillon et al., 2020; Semlyen & Kunasegaran, 2016), which can be demonstrated by using the correct pronouns and terminology, and not making inappropriate comments about their identities or bodies (Johnson et al., 2020). For example, some TMNB patients reported that practitioners who affirmed their gender identity reduced both their levels of discomfort and dysphoria (Dhillon et al., 2020). Additionally, providing further training on working with trans+ people, such as including different bodies in medical textbooks, can improve providers' understanding of trans issues and the respect and sensitivity shown to trans+ patients. Whilst waiting for training to be implemented, providers should make effort to inform themselves about best practices for trans+ health. However, some providers are not only inexperienced in practice, but also report unwillingness to provide healthcare for TMNB. Shires et al. (2019) found that a lack of training and knowledge was not associated with unwillingness to provide CCS to TMNB patients, but bias and beliefs about transgender people was. Therefore, it is important to tackle transphobia among healthcare providers to mitigate negative beliefs about trans people before providing them with training and education around trans health (Shires et al., 2019).

## 2.6 Discussion

This scoping review provides one of the first comprehensive accounts of TMNB experiences of CCS from both a patient and provider perspective. This review highlighted a myriad of negative experiences suffered by TMNB when accessing CCS. Many of these were similar to those of cisgender women such as worries around physical pain, sexual trauma, and embarrassment; however, experiences unique to TMNB were also shared (Berner, Connolly, et al., 2021a; Dhillon et al., 2020; Kerr et al., 2020). Circumstances such as experiencing poverty, homelessness or sexual assault, or being neurodivergent are associated with a lower uptake of CCS, and are also more common among TMNB (Kerr et al., 2020). The findings highlight how TMNB are often subject to negative experiences with CCS due to trans-specific barriers. For example, TMNB often experience a higher level of pain during screening due to testosterone use which causes vaginal atrophy; the thinning and drying of vaginal walls which can increase pain during penetration (Berner, Connolly, et al., 2021a). Additionally, TMNB may experience gender dysphoria due to the focus on genitalia and may feel heightened embarrassment at HCPs seeing this area of their body (Connolly et al., 2020; Weyers et al., 2021). Furthermore, TMNB are less likely to provide adequate cervical samples which may mean they need to repeat the potentially distressing procedure (Gatos, 2018; Reisner et al., 2018). This highlights the need for trans people to be given equal but not identical care (Caulfield et al., 2016). Trans+ people often experience additional systematic barriers to CCS. For example, all people registered as female with their GP automatically receive an invitation every three years; however, trans men who are registered as male do not receive this invitation despite potentially needing this service (Public Health England, 2021). Additionally, GP systems tend to offer binary gender classifications which means gender diverse people must select ‘male’ or ‘female’. This means that not all TMNB receive an invitation to screening, which shows that the current invitation system is a barrier to accessing screening (Public Health England, 2021). This systematic denial of the existence of trans people creates distrust within the healthcare system, which can be further exacerbated when undergoing uncomfortable procedures such as CCS (Bernstein et al., 2017).

## 2.7 Implications

This review indicates important implications for healthcare services and education. Positive experiences result from accessing transspecific screening clinics, or providers who behave in a sensitive and respectful way with patients. This shows that the attitude providers have towards trans patients can affect experiences of CCS; therefore, improving health education is required (Roznovjak et al., 2023). This should include teaching providers to discuss options with their patients which may ease physical and emotional discomfort (Potter et al., 2015), such as offering self-insertion, to be accompanied by a trusted friend, and improving trauma informed care. Additionally, education on appropriate behaviour is required, such as avoiding heteronormative assumptions or inappropriate curiosity. Improving education on trans+ health will also help to reduce potential biases or prejudices, whether conscious or unconscious, held by HCPs, which in turn will improve trans+ peoples experiences of, and trust in, health services. Furthermore, TMNB patients report feeling more welcome when they are represented in clinics, waiting rooms or correspondence (Dhillon et al., 2020). Therefore, the use of inclusive policy documents, indicators of being trans friendly such as including trans+ people in leaflets, posters or invitation letters, or offering gender neutral bathrooms, can help TMNB to feel included and comfortable when accessing CCS (Potter et al., 2015). Lastly, removing systemic barriers, such as updating the current invitation system to ensure that TMNB who are registered as male receive an automatic invitation to screening, would make the procedure more accessible, and thus improve the overall experience and future uptake. Electronic systems should also be updated to ensure that contact with patients uses their correct name, pronouns, titles and gender (Carroll et al., 2023). Therefore, multiple changes within the health services are required at a systematic and societal level, which may in turn improve TMNB's experiences of CCS.

## 2.8 Limitations

The lack of published literature in this area is a potential limitation of this review as many TMNB experiences have not yet been captured, and thus cannot be explored within this review. Additionally, 3 papers (Agénor et al., 2016; Peitzmeier et al., 2017, 2019) and a further paper and conference abstract (Berner et al., 2021c; Berner, Connolly, et al., 2021b) used data from the same participants which potentially limits the diversity of participants included in this review. Further, the majority of participants of the papers included in this review were recruited from trans+ specialist clinics which provide cervical screening, gender identity services or trans+ specific organisations, which require participants to have access to and be engaged with these services, and thus important experiences from trans+ people who are not connected with, or who are unable to access, services are not represented.

Furthermore, the research on provider perspectives required providers to be interested in research about trans health. This is a potential sample bias because those with negative feelings towards TMNB may not have responded to calls for participants. Additionally, all research with providers was undertaken in the US and Australia, both of which are relatively accepting of trans+ people (Flores, 2021). Therefore, studies on provider perspectives in cultures that are less tolerant of TMNB were not captured.

Requiring research to be published in English language may also have excluded research from other countries. While this review did not impose any geographical exclusion criteria, all the research took place in the Global North, which means TMNB people from the Global South are not represented. TMNB living in countries with less tolerance towards LGBTQ+ people may experience adversity when accessing CCS or may be denied this altogether. Further, although some researchers made efforts to recruit a diverse group of participants, such as Peitzmeier et al. (2019), who aimed to recruit older trans+ patients and trans+ people of colour, the majority of participants in this review were white and young (aged under 30); therefore, the experiences of older adults or people of colour may not be represented. Therefore, this review is limited to the experiences of young, white TMNB living in developed countries. Until the research evidence base grows, primary studies could ensure that a diverse group of participants are recruited, such as by recruiting from settings outside of trans-specific clinics and recruiting people with multiple marginalised identities to create a wider understanding of TMNB experiences of CCS.

## 2.9 Conclusion

This review has highlighted the ways in which CCS often fails TMNB people. Individual barriers, such as gender dysphoria, can be exacerbated by systemic barriers that make practical aspects of accessing cervical screening difficult. Many of these experiences were similar to those of cisgender women such as worries around physical pain, sexual trauma, getting time off work and feeling embarrassed (Dhillon *et al.*, 2020; Kerr, Fisher and Jones, 2020; Berner *et al.*, 2021a). However, many of these experiences can be exacerbated by various elements related to having a gender identity different from a cisgender woman. Additionally, a number of circumstances such as experiencing poverty, homelessness or sexual assault, or being queer or neurodivergent are all factors associated with a lower uptake of CCS, as well as being more common among TMNB (Kerr, Fisher and Jones, 2020). Thus, it is important to research and understand the different experiences of TMNB when accessing CCS. Improving trans+ peoples experiences with and uptake of CCS should involve a multi-level approach including medical education about trans health, health service policy change such as modifying the procedure to make it more appropriate for different bodies, as well as societal change in attitudes toward trans+ people.

## 2.10 Summary of the literature review

This review highlighted the complexity of TMNB experiences of accessing and attending CCS, as evidenced by the multitude of often interlinking factors and the heterogeneity between TMNB patients’ experiences. Undertaking further UK research is vital because, as evidenced by the literature review, the current understandings of trans+ experiences of screening in the UK is limited to participants who access trans+ specific clinics, or who are connected with gender identity services or trans+ organisations. Further, the differences in health services, and thus research findings, between the UK and other countries impacts trans+ experiences of these health services. Additionally, qualitative research is important to assess TMNB experiences, thoughts, and feelings about CCS and the reasons underpinning these due to the vulnerable nature of the procedure which makes understanding experiences to be highly important when developing new policy and practice.

The following research questions were developed as a result of the findings of this literature review:

Primary research question

* What are the experiences of transgender men and non-binary people when accessing and attending cervical cancer screening in Northern England?

Secondary research questions

* What can we learn from participants’ experiences to better understand and support future cervical screening appointments?
* What factors influence whether the screening procedure is positive, neutral, or negative?
* What improvements, modifications or changes do TMNB think are most important to improve these experiences?
* What are the implications of this for future policy development and changes to health care practice within the NHS?

# Chapter 3- Methodology

Methodology is a vital part of empirical research to allow readers to understand the underpinnings of the research through exploring theory which influenced its undertaking. Methodology refers to the overarching framework in which the research is situated and which affects how research is conducted (Braun and Clarke, 2013). This study is situated within the qualitative research paradigm, drawing upon social constructionism, intersectional theory, queer methods, and queer sociology. This chapter provides an outline of the methodology used within this thesis and a discussion of how these decisions were made.

## 3.1 Qualitative paradigm

Undertaking research requires making decisions about the methodological underpinnings, such as which paradigm the research is situated within. A research paradigm refers to the general philosophical assumptions shared by a research community that influences the research design and procedure (Braun and Clarke, 2013; Creswell and Creswell, 2018). There are two main research paradigms in social science research: quantitative and qualitative, which provide guidance to help researchers to design appropriate research. Quantitative research uses numerical data to develop generalisable laws about an observable world (Creswell and Creswell, 2018), whereas qualitative research focuses on subjective experiences through “verbal or visual expressions, actions or writings” (Salmons, 2016; p3) to provide a deeper insight into phenomena. Additionally, qualitative research focuses on understanding the meanings that individuals place upon social phenomena through exploring opinions, attitudes and views ascribed to that phenomena (Creswell and Creswell, 2018). The use of the qualitative paradigm is more suitable than the quantitative paradigm when trying to understand meaning and experiences, as participants are able to share their own thoughts, experiences and perceptions and focus on what is important to them, rather than these being pre-framed by the researcher, such as in a questionnaire (Braun and Clarke, 2013). Further, quantitative research focuses on numerical data and statistical interpretations using a reductionist, objective lens, whereas qualitative research is concerned with nonnumerical data and interpretation which value subjectivity, emotions and individual perspectives (Leung, 2015). Whilst feelings and experiences can be considered using quantitative research, the data and thus findings it provides are often limited to those pre-framed by the researcher, rather than allowing participants themselves to share and emphasise that which is important to them. Therefore, qualitative research allows a more meaningful analysis of human experience, which this thesis is concerned with, through allowing participants to share their own experiences without arbitrary limits, which enriches the findings.

The use of the qualitative paradigm is important within health research in order to understand participants’ experiences of health, illness, disability and/or treatment (Holloway and Freshwater, 2007). Qualitative research aims to understand the meanings that participants place upon phenomena through interpreting richly detailed and complex data provided by each participant, thus it places value on subjectivity (Braun and Clarke, 2013). This means that using qualitative approaches in health research facilitates a deeper understanding of patient attitudes towards, or experiences of, health conditions, interventions, services, policy and context (Flemming *et al.*, 2019). Understanding underlying issues related to health experiences is necessary for the development of policy and practice to improve them (Holloway and Freshwater, 2007). Qualitative research is an effective way of understanding patient experience and attitudes as we can ask broader questions about their thoughts, rather than relying on interpretations of restrictive quantitative data which do not represent the patients meaning (Taylor and Francis, 2013; Salmons, 2016). The use of a qualitative paradigm also allows trans+ participants to provide their own experiences in their own words and in a way that they control (Fraser and Taylor, 2020). This is especially important among underserved, vulnerable and/or oppressed groups who are seldom given the opportunity to do this so that their experiences are also represented in research (Connelly and Clandinin, 1990; Liamputtong, 2019; Fraser and Taylor, 2020). Therefore, the use of the qualitative paradigm allows deeper understanding and explorations of patient experiences, which is important within cervical screening research as understanding barriers and facilitators to screening is necessary to improve screening uptake (Overcash, 2003).

Conducting qualitative research requires human connection and the development of a rapport, which is important when studying sensitive topics and/or vulnerable groups to help the participants to feel comfortable whilst discussing potentially upsetting topics (Taylor and Francis, 2013). I believe that the ability to develop trust whilst discussing sensitive topics is a more appropriate manner of research than the disconnect between the researcher and participants within quantitative research, for example methods such as a survey do not allow the developing of connection between researcher and participants due to the minimal contact between them. Having this connection is especially important within this study as trans+ people have historically been overlooked or misrepresented in research (Adams *et al.*, 2017; Bauer *et al.*, 2019) and thus participants may have mistrust in research and concerns about its undertaking, the aims or future use of research, and thus may benefit from developing trust with the researcher.

Finally, the position of qualitative research as rooted in critical philosophies such as phenomenology, social constructionism or social interactionism allows for more insightful, complex and diverse understandings of gender and sexuality (Barker, Richards and Bowes-Catton, 2012). For example, the use of qualitative research allowed for self-defining of gender, for example within this project participants were asked “how do you define your gender?”, rather than pre-deciding gender categories which participants would have to fit themselves into. It is for these reasons that this research study is situated within the qualitative paradigm.

## 3.2 Ontology

This PhD study is underpinned by a relativist ontology and social constructionist epistemology. Ontology refers to theories about the world and the nature of reality; a realist ontology assumes that the world is knowable and that there is a single truth which can be uncovered through research, whereas a relativist ontology assumes that there are multiple realities and thus no single truth (Braun and Clarke, 2013). A researcher’s ontological assumptions determine whether or not they believe that reality exists separately from human experiences, practices and understandings or whether they believe it cannot be separated (Braun and Clarke, 2013). For example, those who take a realist approach believe that absolute truth can be uncovered through research, whereas relativists would argue that this is impossible as there are multiple constructed realities rather than a singular, presocial reality, and that research is unable to get beyond these constructions as the world exists and creates meaning through human interaction (Braun and Clarke, 2013). As demonstrated in the extract below, I took time to consolidate my understandings of ontology and epistemology and considered various approaches before deciding on relativism and social constructionism.

|  |  |
| --- | --- |
| Extract from reflexive diary: 31/01/22 | I’m still struggling to understand ontology and epistemology and what approach my beliefs fit best with. I’ve considered critical realism as I liked the idea of it, but some critical realist researchers have used it to say that trans people won’t ever ontologically be their gender. I strongly oppose this and don’t want to use something that’s been associated with transphobia. I still think relativism and social constructionism aligns with what I believe the most. |

This study takes a relativist approach as I take the position that there is no single reality, but rather individuals construct their own realities which are socially located and dependent on meaning and context. I take a multiple reality perspective which means I believe that individuals construct and interpret their own realities and therefore there are as many realities as there are people (Levers, 2013). Therefore, this research study places value on individual experiences, perceptions, meanings, and the contexts in which they take place in order to co-construct subjective findings which represent individuals’ meanings, rather than aim to uncover a singular truth. This ontological stance, alongside a qualitative research paradigm, allows for a greater understanding of trans+ experiences of healthcare by considering trans+ experiences in context and through meaning expressed by trans+ people themselves. This is vital when considering the complex factors surrounding trans+ health and health inequality it as it recognises the different perspectives and meanings trans+ people place on their experiences and recognises the heterogeny between these, thus allowing a greater and more detailed understanding of such experiences.

## 3.3 Epistemology

Epistemology refers to the criteria for what constitutes knowledge, including what type of knowledge is legitimate or meaningful and what it is possible to know (Lykke, 2010; Braun and Clarke, 2013). Positivist epistemologies suggest there is a single truth which can be uncovered through research, whereas constructivist epistemologies believe that absolute truth is impossible as truth is dependent on context and individual people’s interpretations which are subjective and influenced by their own life experiences (Braun and Clarke, 2013).

This thesis takes a constructivist epistemological stance due to my belief that an objective truth is unable to exist because people construct their own meanings based on socio-historical contexts and life experiences. Unlike positivist epistemologies which aim to uncover an objective truth, constructivist epistemologies value subjectivity and recognise that research can explore multiple meanings that participants place on phenomena, thus constructivist research aims to interpret individual realities based upon insights from participants. Further, positivist epistemologies suggest that researchers should be objective observers of an objective reality, whereas I take the position that researchers are unable to be objective due to our existence in the social world, which means we are unable to remove sources of bias and instead should be reflexive on how our own experiences influence our research (Braun and Clarke, 2013), therefore I have provided an in-depth reflection in Chapter 6.3: Strengths, limitations and reflexivity. Constructivist epistemologies value subjectivity in research above objectivity, and thus this epistemology is the most appropriate for this PhD study.

Social constructionism is a constructivist epistemology which has been developed and influenced by a various traditions, including psychology and sociology, and thinkers, such as Foucault who discussed social constructionism in the context of sexuality and mental illness (in Burr, 2003) and Judith Butler who discusses the social construction of gender (Butler, 1993, 2024). Social constructionists argue that knowledge is historically and culturally specific rather than being a reflection of an objective and observable single reality (Gergen, 1973). Social constructionism views the world as constructed through social norms, interaction, discourse and other processes within the societies in which we live (Braun and Clarke, 2013). This means that knowledge is socio-politically, culturally and historically specific as it is dependent on the social norms in the culture and time period in which it is produced (Burr, 2003). For example, a social constructionist perspective challenges the view that categories created by humans, such as sex and gender, reflect a ‘real division’ (Burr, 2015). Positivists view sex assignment as a description of observed facts: they believe that observing genitalia to assign a sex is simply describing what already exists (Butler, 2024). In contrast, social constructionism casts a critical lens on binary categories of sex and gender and instead highlights how these ideas were created by humans placing meaning on bodies, rather than on an underlying objective truth (Burr, 2015). Butler (2024) argues that bodies do not exist outside of social meanings that people ascribe to them, and that meanings around sex and gender are created through social constructionism. Further, Butler, (2024) argues that positivism considers bodies to be decontextualised, meaning that positivists ignore the lived body and experiences of the body and gender and the processes which have developed into what gender means within individuals and society. The construction of gender is evidenced by the concepts of sex and gender differing historically and culturally (Burr, 2015), meaning that research about gender would not uncover an ‘objective truth’ but would rather reflect the experiences of gender in the specific social, historical and cultural context in which the research takes place. Therefore, social constructionists argue that research cannot produce universal knowledge about a single truth, but instead can aim to understand meanings of phenomena in a specific context.

This thesis places importance on the influence of the context in which participants’ experiences are produced. Considering context is especially important in health research as developing policy and practice to improve health experiences requires an understanding of the underlying issues, which can only be addressed when people are asked about them (Holloway and Freshwater, 2007). Further, social constructionist approaches to gender, such as that described by (Butler, 2024) allows for a deeper understanding of trans+ lived experiences as it recognises the context in which trans+ people exist, and social meanings placed on trans+ identities, which influence their experiences of institutions such as healthcare. Therefore, this research study is underpinned by a qualitative research paradigm and social constructionist epistemology.

## 3.4 Intersectional theory

Additionally, this thesis draws on intersectional theory, which has been used to develop deeper understanding of experiences shared within the participants’ stories (Chadwick, 2017). The term “intersectionality” is credited to Crenshaw, (1989) originally to describe the intertwined discrimination experienced by Black women because of both their gender and race. For example, Crenshaw stated that “intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects” (Crenshaw, 2017) thus highlighting that experiences are impacted by power imbalances which are impacted by people living with multiple intersections, such as being Black and a woman. Intersectionality highlights that Black women’s experiences differ from the experiences of white women and Black men due to the intersection of two identities (being Black and a woman) which are situated with less power than other identities (being white or male). The aim of an intersectional approach is to consider multiple identities together to examine how marginalised identities intersect to produce outcomes, such as experiences of inequality or discrimination (Fish, 2017).

The use of intersectional theory is important within health research as multiple discrimination due to multiple marginalised identities can negatively affect health and health care (Fish, 2017). Providing effective and appropriate care requires an understanding of peoples identities and experiences, and failing to do so may lead to missing health risks related to their identities (Ng, 2016). Therefore, the use of intersectional theory can lead to a more comprehensive understanding of patient health and healthcare needs (Ng, 2016).

Intersectional theory may also provide important insights into LGBTQ+ health (Fish, 2017). The lack of consideration of multiple marginalised identities among LGBTQ+ people in health research has led to the homogenisation of LGBTQ+ communities (Fish, 2017). Often, health research neglects the differences between gender and sexuality as well as the various identities under the LGBTQ+ umbrella, as well as ignoring how their LGBTQ+ status intersects with other marginalised identities such as race, ethnicity, age or class (Fish, 2017). Ensuring that health inequalities among all LGBTQ+ people are addressed requires an understanding of the experiences of LGBTQ+ people with multiple marginalised identities to create modifications that will work for everyone. Therefore, I apply an intersectional lens to this study to understand multiple, intersecting, layers of inequality that the participants may have experienced. My approach to this research topic and recruitment was framed by intersectionality, for example I ensured that I collected demographic data to be able to draw upon intersections of trans+ identities and other marginalised characteristics throughout the research. Further, I aimed to recruit a diverse participant group. This allowed me to explore how different intersections affect trans+ peoples experiences of health care, rather than viewing all trans+ people as a homogenous group and ignoring differences in personal characteristics. Within the Discussion Chapter, I draw upon previous literature discussing trans+ people with multiple marginalised characteristics in order to examine how this research contributes to knowledge, and to explore ways that living at various intersections may impact health experiences. Therefore, intersectionality is a vital part of this research and, I believe, should be included within all research studies.

## 3.5 Queer sociology and queer methods

The approach to research design, data collection and analysis in this thesis was also inspired by various queer/LGBTQ+ methods thinking which details queer sociology and/or appropriate methods for conducting research with queer participants (Browne and Nash, 2010; Compton, Meadow and Schilt, 2018; Stall *et al.*, 2020). Queer sociology refers to a strand of sociology that aims to blend queer theory and sociology by building on queer, feminist and critical race theories to explore how social locations can shape a person’s experience gender and sexuality (Compton, Meadow and Schilt, 2018). Like queer theorists, queer sociologists believe sexuality and gender are social constructions, however in contrast to queer theorists, they do not want to deconstruct these identity categories, but instead place importance on them (Compton, Meadow and Schilt, 2018).

Implementing effective health interventions requires an understanding of the needs of sexual and gender minority individuals, which can be more effectively done when considering queer and LGBTQ+ methods (Fish, 2017; Compton, Meadow and Schilt, 2018; Stall *et al.*, 2020). Traditional methods and methodology can be “queered” in order to be more appropriate for LGBTQ+ people, rather than only using queer methods simply because they are queer (Heckert, 2010). For example, queer sociology and queering methods have influenced how participants are recruited. Early LGBTQ+ health research involved recruiting LGBTQ+ participants from queer spaces, meaning that the research only reflects LGBTQ+ people who feel comfortable accessing queer spaces whilst ignoring those who are not comfortable enough or who are not out (Stall *et al.*, 2020). This can result in skewed findings which may mislead other researchers, policymakers, and practitioners as this research is only reflective of the experiences of people who are comfortable with engaging in queer spaces. Therefore, queer sociology and queering methods place importance on recruiting from non-queer specific places in order to provide insights into the experiences of queer people who are not connected with the queer community. As noted in the methods chapter, I tried to reach participants who were not connected with queer spaces, such as by using various social media and asking participants to share with others who may be interested. Further, as discussed in Chapter One, study is concerned with trans+ people who do not access trans specific clinics, and thus all recruitment was undertaken outside of trans specific clinics, which were often the main recruitment areas in previous research on trans+ health.

Additionally, engagement with literature on queer methods and queer sociology has influenced the terminology I have used throughout this study, for example using the terms “transmasculine” or “trans and non-binary”, which centre a persons gender, rather than terms such as “gender minority AFAB” which centre sex assigned at birth, which forms a part of ensuring research is undertaken sensitively and respectfully. Queer sociology and queer methods textbooks such as Stall *et al.*, (2020) detail the importance of resisting cis/heteronormative assumptions when designing research, such as having only male/female gender categories when collecting demographic data, and instead highlights how to create inclusive data collection instruments. I gave participants the option to self-define their gender identity rather than forcing people to choose boxes which may not fully encapsulate their identity. This may have helped participants to feel more comfortable being able to express their gender, rather than being confined to the pre-set genders conceived by researchers. I also reflected on my position as a queer researcher, and how this may affect research design, data collection and data analysis, as discussed in Chapter 6.3: Strengths, limitations and reflexivity. For example, I considered queer sociology and queer methods when deciding to share my own gender experiences with participants, which multiple participants shared made them feel more comfortable to know that the research was being done by someone in the community as they were less afraid of the research being used to harm queer people, such as to force unwilling trans+ people to attend cervical screening. Therefore, queer methods and queer sociology greatly impacted the design of my research, as well as participants’ experiences of being research subjects as shown in the following reflexive diary extract.

|  |  |
| --- | --- |
| Extract from reflexive diary entry: 21/11/22  First interview | Participant felt comfortable with me including saying that they shared things with me that they felt were too personal to share with doctors or other health professionals. Developed trust and rapport, partly due to relating to each other’s experiences of gender. |

To summarise, this PhD study uses a qualitative methodology, underpinned by social constructionism, intersectionality and queer sociology/methods to provide an in-depth exploration of trans+ peoples experiences of cervical screening in the North of England. This methodology was chosen as qualitative research is vital to explore trans+ health experiences, and thus develop improvements which are meaningful to trans+ people. Further, the combination of social constructionism, intersectionality and queer sociology/methods ensures that the findings are grounded in trans+ experiences and reflect the diversity of the trans+ community.

# Chapter 4 - Methods

This chapter discusses the methods used to recruit participants, collect and analyse data and ethical considerations for this doctoral study. Each element of the method used is outlined alongside reasons why each decision was made.

Whilst considering which methods would be most appropriate for this study, I spoke with other queer researchers about recruitment and data collection, as well as reading widely on literature about the ethics of conducting research with trans+ people. This occurred both at two conferences I attended which discussed queer health and other queer research, as well as through connections made via social media. I also considered ways in which I, as a queer researcher, would feel comfortable engaging in research about potentially distressing topics and implemented these (see below). Further, I discussed my methods with non-academic queer friends to see whether this felt appropriate for those outside of the academic sphere. This helped to shape the way I conducted this research. For example, I and other queer people I spoke with, find comfort in knowing that the research is being done for the “right reasons” i.e., that research is being conducted by people who care about the LGBTQ+ community and are inclusive of trans+ people within this, and who want to improve lived experiences for trans+ people, rather than people who may potentially do harm. Therefore, I gave participants the option to ask questions within the expression of interest form, as well as to meet with me prior to their involvement. I kept these conversations, conferences, and the literature I had explored in mind whilst designing and conducting this research.

## 4.1 Sample and recruitment

### 4.1.1 Sample

I aimed to recruit a sample of around 15-20 people from a diverse range of backgrounds who live in the North of England. The sample size was determined through engagement with information power which refers to the concept that the more power information holds, the lower sample size is needed (Malterud, Siersma and Guassora, 2016). This was used as an alternative to data saturation, which refers to ending data collection once no more new information, themes or patterns are being uncovered, due to the nature of this study. For example, this study aims to share insights into a diverse group of experiences rather than describing all possible phenomena or generating a theory, and thus the goal was to ensure that data collected is rich, detailed and meaningful, rather than reaching a specified number (Malterud, Siersma and Guassora, 2016; Ahmed, 2025). Further, data saturation is not consistent with the values and assumptions of reflexive thematic analysis, which is the analysis method used within this study (Braun and Clarke, 2019b). Information power is impacted by five dimensions: (a) study aim, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy (Malterud, Siersma and Guassora, 2016). For example, a narrower study aim means that a smaller sample size is required to reach sufficient information power (Malterud, Siersma and Guassora, 2016). Thus, the narrow study aim alongside the specificity of the sample required necessitate a smaller sample size. However, the quality of the interview can also impact information power, for example information power may be easier to reach for a more experienced interviewer, thus requiring less participants. Although as a PhD student I had limited interview skills, I benefited from being an insider in the topic and being able to relate to and develop rapport with participants, and I undertook training and pilot interviews. Through considering various dimensions which impact information power, a sample size of 15-20 was decided.

The sample criteria (shown below) were chosen because, as shown by the scoping review in Chapter 2, most of the literature on trans CCS is based in the USA, or the South of England, and includes relatively young, white trans people who access screening through trans-specific clinics. This highlights a gap in academic knowledge of CCS experiences of trans+ people who do not fall into these categories, and therefore I aimed to recruit a more diverse sample. After reviewing the literature, as presented in Chapter 2, it became clear that the age range for this sample would be 25+. This is in line with the CCS programme in the UK, which invites people with a cervix to be screened at ages 25-64 (Public Health England, 2021). I considered including people who were under 25, as some authors (eg. Berner *et al.*, 2021) argue that the attitudes of people approaching screening age are important to include, however this thesis is concerned with experiences of accessing and attending screening rather than perceptions from those who are not yet eligible for screening, in order to see how trans+ people are treated in non-trans-specific screening appointments. Additionally, the open-ended age bracket allows people who have accessed CCS but are now over 65, as well as allowing the inclusion of people who continue to have screening above the age of 65, which is available for people aged 65+ who have never accessed CCS before, or whose last screening result showed abnormal cells (Jo’s Trust, 2018). Additionally, all participants live in the North of England, which includes Yorkshire and the Humber, the North East and the North West. I focused on trans+ people from this area because most of the literature on trans CCS, as well as more general trans+ health, is based in the South of England, and mainly in London and Brighton. Whilst a research project looking at cervical screening for LGBTQ+ people has been conducted in Manchester, this focused on the acceptability of urine testing for lesbian and bisexual women and trans+ people and thus there is a limited understanding of trans+ peoples experiences of screening in the North of England. The North in general was chosen based on the existence of multiple trans-inclusive clinics in the South of England, such as 56T, CliniQ and Clinic T, which may provide a better quality of care than non-trans specific clinics, meaning that TMNB living in the North may have different experiences to those in the South of England due to the absence of these specialist clinics.

### 4.1.2 Recruitment

15 trans+ participants were recruited through purposive and snowball sampling. Purposive sampling refers to selecting participants based on specific criteria which means they are able to provide experience and insight into the research area (Given, 2012). Whereas, snowball sampling refers to asking participants to share the research study with other potential participants (Given, 2012). The combination of purposive and snowball sampling was chosen to ensure that the call for participants was shared as widely as possible to reach many potential participants with relevant experience. Participants were recruited via social media and email lists. I shared the advert (as presented in Appendix 5) and a link to the project website ([www.transscreeningproject.wordpress.com](http://www.transscreeningproject.wordpress.com)), within which participants were able to access the participant information sheet (presented in Appendix 6) and register their interest in the study, on X (formerly Twitter), Reddit, and LGBT+ mailing lists. 29 potential participants shared their details on an expression of interest form, whom I emailed with further information and the offer to meet with me to discuss their involvement. The expression of interest form also gave the opportunity for participants to ask questions, for example one participant used this to query whether they were eligible as they no longer had a cervix but had attended screening in the past. Following these emails, I did not hear back from 14 people, and I met with 15 participants via telephone or Google Meet (method decided by the participants) to offer the chance to ask any further questions about myself or the research, and, if applicable, to collect demographic data including gender, pronouns, ethnicity, age, whether or not they have a disability, and area in which they live. This seemed to be an effective strategy for developing trust as multiple participants asked questions about my own gender and the reasons why I chose to undertake this study. Multiple participants shared that they found speaking to me prior to the interview to be useful as they could be sure I was engaging in the research for the right reasons and that they were not participating in research where the researcher may not be sensitive to or understanding of trans+ issues. This may also have helped to develop rapport as multiple participants seemed to feel easily comfortable when discussing their cervical screening with me.

The recruitment posts were initially listed on the 11th of November 2022, the final recruitment took place mid-March 2023, and the final data collection took place on 29th of March 2023. The study was shared widely across Twitter, which was where the majority of participants were recruited from, as the original post was shared over 200 times. The post was shared by various types of account, such as area specific trans groups (i.e. @HallamLGBTStaff, @MCRPrideProtest, @TUoSLGBT and @TransBarnsley), prominent figures in trans+ health or sexual health (i.e. @SophieSGaler and @HelenWebberly), organisations which aim to improve trans inclusivity in health care and education (i.e., @PrideInSTEM, @GenderGP, @PrideProgress and @HealthBeetle and the LGBTQ+ cancer charity @OUTPatientsUK) as well as trans people and allies. The recruitment information was also shared on the following subreddits after gaining permission from the subreddit admins: r/TransMasc, r/LGBTStudies, r/HonestTransgender, r/Genderfluid, r/SampleSize and r/HealthyHooha. Some participants mentioned that information had been reposted to other sites, including Instagram and Facebook. I also asked people to share the information within their circles so that people who do not use social media/follow the accounts who shared the study could also consider taking part in the study.

Prior to beginning recruitment, I had aimed to adopt a method used by Peitzmeier *et al.*, (2019) to recruit a more diverse participant group. This method involves slowing recruitment by not recruiting the first participants to contact with interest in the study, but instead waiting for a longer period of time to allow more people to show interest, collecting demographic data and selecting a diverse group of participants. This allows individuals from underserved groups, such as older trans+ people or trans+ people of colour, to respond to the call for participants and thus allow a more diverse range of experiences to be included in the study by purposively selecting participants. However, this method was not used as less people than I initially expected expressed an interest in participating in the study, and thus it did not seem appropriate to leave these people waiting so they were given the opportunity to participate.

## 4.2 Inclusion and exclusion criteria

Eligible participants were:

* Aged 25+.
* Identified as a transgender man, transmasculine, non-binary, genderqueer, agender or another self-defined gender
* Had a cervix, or tried to access and/or attended CCS prior to removal of the cervix
* Lived in the North of England (which includes Yorkshire and the Humber, the North East and the North West)
* Could read, speak, and understand fluent English
* Could give informed consent to the study

Participants were not eligible if they:

* Were assigned male at birth
* Were unable to read, speak and understand fluent English
* Did not live in the North of England

## 4.3 Description of participants

15 trans+ participants who live in the North of England took part in this PhD study. Participant characteristics can be seen in the table below. Participants were asked to self-define their gender and pronouns. Some participants use multiple sets of pronouns, such as he/they or they/she/he, which will be used interchangeably throughout this thesis. Participants were also asked whether they consider themselves to have a disability, to which 13/15 participants answered “yes” and gave responses that, in some cases, have been broadened to maintain anonymity. Participants were also asked their age, whether they live in a rural area or a city, and whether they had accessed screening prior to the study. One participant had not yet accessed cervical screening; they had been invited but had not yet felt able to attend.

Table 1. Participants characteristics

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Pseudonym | Data collection method | Self-defined gender | Pronouns | Age | Self-defined ethnicity | Self-defined disability | Location | Attended screening? |
| Andrew | Focus group | Fluid transmasc | Any - primarily he/they/she | 25-30 | Caucasian | Neurodivergent | Rural | Yes |
| Blue | Focus group | Non-binary | They/them | 30-35 | White British | Chronic mental illness, chronic physical disability, chronic pain, neurodivergent | Small city | Yes |
| Bruce | Focus group | Trans non-binary | They/them | 35-40 | White British | Neurodiverse | City | Yes |
| Dave | Interview | Non-binary / agender | They/them | 30-35 | White British | No | City | Yes |
| Ethan | Interview | Trans man | He/him | 40-45 | White British | Totally blind, sensory, physical and mental health conditions | Small city | Yes |
| G | Interview | Non-binary | They/them | 25-30 | White British | Hearing impaired, mental health condition, physical condition | Rural | Yes |
| Jack | Interview | Trans masculine non-binary | They/them and he/him | 25-30 | White European | Neurodivergent and chronic mental health conditions | City | Yes |
| Jamie | Focus group | Transmasc non-binary | They/them | 25-30 | White British | Physical disabilities, chronic illness | City | No |
| Jocelyn | Interview | Androgynous with some femme and some masc days | Any/they/she/he | 40-45 | White | Mental health conditions | City | Yes |
| Kit | Focus group | Non-binary | They/them | 25-30 | White British | Neurodiverse and visual impairment | Rural - town | Yes |
| L | Interview | Agender and outside of the gender binary | They/them | 25-30 | White British | No | Rural | Yes |
| Leo | Interview | Non-binary | They/them | 30-35 | White British | Invisible chronic illness | City - from rural | Yes |
| Robin | Interview | Transmasc non-binary | They/them | 35-40 | White British | Neurodiverse | Rural | Yes |
| Ryan | Interview | "How do you describe your gender" "with difficulty”, if pushed – non-binary demiguy | They/them | 35-40 | White British | Neurodiverse, autoimmune condition | City | Yes |
| Toothless | Interview | Trans man | He/they | 25-30 | British Japanese | Neurodiverse, neurological condition, mental health condition | City suburb | Yes |

## 4.4 Data collection

As discussed in Chapter Three: Methodology, the overarching goal of data collection was to develop “thick” data on trans+ peoples experiences of cervical screening. Data were collected primarily by two methods: 1. one-to-one semi-structured interview; or 2. online asynchronous focus group. Participants were given a choice of method to ensure that each participant was able to participate in a way they were comfortable with. Further, the use of more than one method of participation is important when developing research which is accessible to disabled people (Rios *et al.*, 2016). During data collection, 10 people were interviewed and five were part of a focus group. The average interview time was 43 minutes. Semi-structured interviews are a form of interview in which some questions are decided previously to create a flexible structure to the interview, however questions can be added as they arise throughout the interview. This type of interview was selected so that there could be a structure to the interview to help ease participants into discussing their experiences of cervical screening, and so that areas of interest which arose could be followed up on with further questioning.

Interviews have been used to explore personal health experiences beyond the boundaries of a questionnaire, including decisions, feelings and experiences of screening procedures with disempowered communities (Overcash, 2003). However, there are also limitations to interviewing. For example, some participants may feel uncomfortable sharing vulnerable and sensitive information with the researcher (Fraser and Taylor, 2020). This is especially true for trans+ people who may have been mistreated within research, and thus may not trust the researcher to treat them with respect (Vincent, 2018a). Therefore, it is important for the researcher to develop a rapport early on to help the participants to feel comfortable sharing their stories (Fraser and Taylor, 2020). As above, I aimed to do this through contact with the participants prior to undertaking the interview, by discussing the procedure of the interview and answering any questions, and by beginning the interview in a more general way.

At the start of the interviews, I explained the procedure to the participants, and asked if they consented to starting the recording. In order to help the participants to relax, the interviews began with a brief discussion of cervical screening in general, rather than their CCS experiences (Ackerly and True, 2010). This is because the building of trust and rapport is necessary for successful interviews (Anderson and Kirkpatrick, 2015). This is especially true within this research study due to the sensitive nature of the topic, and the historic discrimination that trans+ people have experienced both in healthcare and health research. I then began to ask deeper questions about their own experiences of cervical screening and what might improve them, as shown in the interview guide in Appendix 7. The interview guide was developed using the literature review findings, as I identified areas of interest for further exploration and gaps in the literature which I thought were important to understand in order to improve cervical screening. Further, I considered how I, as a queer person, would best engage with an interview about cervical screening, as well as checking with friends outside of academia that the guide was appropriate and understandable. This reassured me that the interview guide was sensitive and fit for purpose. I also probed for further information throughout the interviews, and multiple participants began to share answers to questions I had not yet asked. At the end of the interview, I asked each participant if they had any questions or anything more to share, thanked the participants and ended the recording.

I conducted a pilot interview, which was included within this study. This allowed me to test the interview guide to check that it was appropriate and to make any necessary edits. The pilot interview went well, for example it lasted over an hour and the participant often answered the next question in the interview guide before I had asked it. This allowed me to prompt further, while also allowing the natural flow of the conversation into further depth as the participants shared more of their experience. Therefore, it seemed that the interview guide was appropriate and useful for answering the research questions and thus I made no edits following this. The pilot interview also allowed me to gain confidence in interviewing as I developed skills in prompting for further information and providing support when they became upset. This is demonstrated below with two extracts from my reflexive diary which detail how I felt before and after this first interview:

|  |  |
| --- | --- |
| Extract from reflexive diary: 02/02/22  Being a participant | Today I took part in an interview as a participant in a sensitive topic regarding LGBTQ+ lives. It was useful to see how to approach this from the opposite side, such as how they want about it, how they supported me, encouraged me to speak, and gave prompts including reminding me I could say no to answering some questions/prompts, and checking that I was okay enough to start and continue. I still feel nervous about starting data collection, but I think I’ve learnt new ways to go about this practically. |
| Extract from reflexive diary: 21/11/02  Pilot interview | I felt really nervous this morning but it went well. I was worried about it not lasting very long, or the participant not feeling comfortable with me, but it went well. I felt a little uncomfortable when asking questions that might be upsetting for the participant, but I made sure they knew they didn’t have to answer and reminded myself that they’d volunteered. We had an interesting conversation about the emotional differences of being trans in a rural area vs a city. Participant felt comfortable with me including saying that they shared things with me that they felt were too personal to share with doctors or other health professionals. Developed trust and rapport, partly due to relating to each other’s experiences of gender. |

To ensure all participants were able to participate in a way they felt comfortable with, I offered participants the option to provide their stories via an asynchronous online focus group. The online focus groups elicited similar data, by using the same questions, as gathered through the interviews but using a different method. Asynchronous online focus groups have been successfully used with vulnerable and diverse participants (Ranieri *et al.*, 2019). Reisner *et al.*, (2018) conducted interviews on CCS for trans men and was told by participants that their friends wanted to partake but did not feel comfortable doing so face-to-face. As a result, they conducted similar research using asynchronous online focus groups. Traditionally, a focus group is a method of data collection in qualitative research where groups of people are asked to discuss their attitudes towards a topic of interest, usually face-to-face (Reisner *et al.*, 2018).

This method was chosen by 5/15 of the participants, for reasons such as struggling to find a time to book in an interview, not wanting to discuss face to face, and wanting to see other people’s responses to get advice from them. I created a page (as presented in Appendix 8), similar to a forum, on WordPress, where I created posts for participants to respond to at a time they chose, as well as being able to respond to other people’s comments and develop their responses. I took care to ensure that the site was secure, such as being password-protected, and that participants were anonymous to everyone except myself, such as by using pseudonyms and reminding them to consider whether their comments could be potentially identifiable. This is discussed in more detail below. Over the two weeks the interview was open for, I posted the same questions listed in the interview guide, with the aim of eliciting the participants stories and experiences of accessing and attending screening, as well as reasons they may not do this. I refined the questions following a number of interviews so that I could add prompts to elicit meaningful thoughts and experiences. The focus group was open from the 30th of January 2023 to 12th of February 2023, to allow participants to provide their answers at a convenient time. In the first week, I asked participants about their experiences and in the second week I emailed a reminder about the focus group and asked questions about potential improvements.

Conducting focus groups online allowed the elimination of some issues with face-to-face focus groups, such as some participants speaking over others (Woodnutt, 2019). Additionally, individuals in face-to-face focus groups get less time to discuss their own experiences because the researcher must move on to let everyone speak (Woodnutt, 2019). In contrast, conducting focus groups online means that individuals were able to give as long answers as they want because they do not have to wait for others to stop talking, thus they are able to provide in-depth answers (Woodnutt, 2019). This also allows participants to have non-disruptive “side conversations” in which they can develop their responses (Gordon *et al.*, 2021). This includes participants offering support, affirmation or advice across comments, which has encouraged others to open up and discuss their thoughts and experiences whilst feeling supported by other TMNB with similar experiences in a study on TMNB self-esteem and body image (Gordon *et al.*, 2021). A number of participants shared that they liked being able to see other people’s responses as they were able to gather advice to use for their own future screenings. Further, the one participant who changed to an interview shared that he had initially selected a focus group due to being able to see other answers. As this focus was open for two weeks, participants were able to think about and further develop their responses, and I was also able to do the same to consider further questioning, allowing further insights to be gained that may not be elicited using traditional focus groups (Woodnutt, 2019, 2020).

Additionally, online focus groups allow greater anonymity than face-to-face focus groups as participants are able to use pseudonyms on their responses and will not see other participants. (Forrestal, D’Angelo and Vogel, 2015; Woodnutt, 2019). This higher level of anonymity has allowed participants to speak more freely and provide more honest answers, particularly regarding sensitive topics (Zwaanswijk and Van Dulmen, 2014; Forrestal, D’Angelo and Vogel, 2015).

Although there are many positive aspects of conducting online focus groups, there are also limitations. Involvement in online focus groups is dependent on participants literacy and access to and understanding of technology, therefore people without this may be excluded from participation (Ranieri *et al.*, 2019). However, LGBTQ+ populations often have good technological skills as they often use the internet to interact with other LGBTQ+ people or look for sexual health information that is not available in other places and therefore should be able to access online focus groups (Reisner *et al.*, 2018). Additionally, the option for interviews will be available for participants who are unable to access the focus group. One participant in this study chose to be part of the focus group but struggled to access it and instead requested to switch to an interview, all other participants were able to access the focus group with ease.

Further, the online focus group required participants to wait until enough other participants had signed up, and thus participants may decide they no longer want to wait or that they are no longer interested in the study. Fortunately, no participants dropped out of this study. This method, over interviews, also had further considerations for confidentiality between participants. For example, I ensured that participants used pseudonyms within the focus group, and I took great care to explain to participants the importance of not sharing identifiable information, such as the city they live in, or clinic they accessed, to ensure that participants did not become identifiable to each other. Information about ensuring anonymity and confidentiality was shared during discussions with participants, as well as on the welcome page (as presented in Appendix 9) so that participants could check back. I monitored the focus group at least three times a day over the two weeks it was open to ensure that participants were not sharing identifiable data or causing harm to other participants such as through inconsiderate comments or arguments; all participants were respectful of each other and careful to stay anonymous and therefore no comments were edited or removed. This also created further work, although this was balanced by not needing to transcribe the focus group data. I was also able to probe for more information, however some of my further questions were left unanswered. Although most comments were replied to and I gathered rich data, more detail may have been gathered through interviews due to the format of a conversation, whereas here participants were potentially able to miss comments. Although, participants were also reminded that they did not have to answer anything they felt uncomfortable with, or did not want to for any other reason, and thus may not have answered similar questions in a potential interview.

The online focus group was created using WordPress.com, with the forum plugin Asgoros, as this site has been successfully used to conduct a number of focus groups (Hancock, 2017). WordPress has been described as a free, secure, accessible and easy to navigate site to allow qualitative researchers to conduct focus groups online (Hancock, 2017). Additionally, WordPress allows anonymity, security and privacy, which is in line with ethical issues, for example through being password-protected and requiring admins permission before accessing the site, collecting minimal data, such as not collecting IP addresses and thus giving further privacy to participants, and giving the option of using a pseudonym to maintain anonymity (Hancock, 2017). Furthermore, the data was downloaded straight into a word file, thus allowing easy accessibility of research data and eliminating any transcription errors and reducing time needed to transcribe (Hancock, 2017).

Both data collection methods were successful in allowing the collection of richly detailed and meaningful data from the participants. The focus group data was easily downloaded into a Word document, which reduced the time taken to transcribe. These were not altered as participants had not shared identifying information. In contrast, I transcribed each interview verbatim, using the automatic transcription service from Google Meet which required heavy editing. Further, I altered some information, such as names of clinics that participants had attended, to preserve anonymity. The transcripts were used to identify four themes through analysis, as explored below.

## 4.5 Data analysis

The data collected by both the interviews and online focus groups were treated as one data set and analysed using reflexive thematic analysis, a data analysis method developed by Braun and Clarke, (2006, 2019, 2022). The decision to combine both datasets was made due to both methods being used for the same aims: eliciting rich data of people’s stories and experiences and perceptions of cervical cancer screening. As above, both methods have been shown to elicit richly detailed data about people’s health service experiences, and often asynchronous online focus groups provide data that is equally, or more, detailed as data collected through interviews (Forrestal, D’Angelo and Vogel, 2015; Ranieri *et al.*, 2019; Gordon *et al.*, 2021). This was also the case for this study, as some interviews involving participants who appeared to be shy or reserved elicited less richly detailed data than focus groups in which participants wrote lengthy answers to each question.

Reflexive thematic analysis (TA) was chosen as it allows the meaning of stories to be explored within context (Braun and Clarke, 2013). Additionally, reflexive TA is situated within a big Q qualitative framework, meaning it is fully qualitative both in procedures and the underlying research values, rather than a small q qualitative framework which discusses qualitative research in a positivist manner (Braun and Clarke, 2021a). A big Q qualitative framework is “most suitable for those who want to explore deep, complex, nuanced meaning and understanding” (Braun and Clarke, 2022; p274). Thematic analysis is not bound to a theoretical paradigm (Braun and Clarke, 2006, 2022) and therefore can be used with the methodology adopted in this PhD study.

Themes have a shared meaning underpinned by a core concept and are co-constructed between the researcher and participants, through the data provided by the participant and the interpretation and analysis by the researcher, to produce a report which represents the meaning in context (Braun and Clarke, 2022). This means researchers are required to be reflexive in how they shaped the research, and must write their thoughts and processes which underpin their interpretation and analysis of the data into the final report (Braun and Clarke, 2021b, 2022). In order to ensure reflection, I kept a reflexivity diary throughout the study in which I detailed thoughts from decision making in the early stages of developing this PhD study, to reflections on data collection and data analysis. An in-depth reflexivity section which explores each of these sections can be found in Chapter 6.3.

Reflexive thematic analysis is a six-step recursive process, meaning that although there are linear steps, conducting reflexive thematic analysis requires movement between each step to effectively analyse the data in a meaningful way (Braun and Clarke, 2022):

1. Familiarising yourself with the data: this involves re-listening to audio recordings, transcribing and re-reading the data and noticing initial patterns and meanings.
2. Coding the data: this refers to organising the data into initial meaningful groups.
3. Generating initial themes: identifying meanings and patterns between codes and beginning to organise codes into themes.
4. Reviewing and developing themes: this involves reviewing the themes to ensure that they are appropriate in answering the research questions and representing the data as a whole.
5. Refining, defining and naming themes: this step involves developing analysis of the themes, defining the scope and focus, and choosing informative and appropriate theme names.
6. Producing the report: writing up the analysis of the research data and ensuring that each theme includes enough supporting data and minimal crossover.

Following these steps, I started by reading and re-reading the transcripts multiple times in order to familiarise myself with the data (step one). I then began to annotate the transcripts with initial interpretations and create codes, such as “avoidance”, “control”, “dread” and “self-advocacy”, which represent the meanings found within the entire data set (step two). Coding was undertaken electronically using NVivo. Here, I began noting patterns from the data and also began to feel the emotional demands of undertaking this research, and reflected on these within the following reflexive diary entry:

|  |  |
| --- | --- |
| Reflexive diary entry: 10/02/23 | It’s common for the participants to share being excited about medical transition but worries about how this will affect their experiences of screening, i.e. will they be taken more seriously because of physical changes, or will they feel worse because they’ll look more masc etc and stand out more. How will hcps react, will they be judgemental of changes? Will they use the right pronouns because they can see they look more masc? Will they feel more pain because of T? It’s so sad that something that should be so exciting and affirming for trans+ people comes with these worries because of other peoples attitudes. And more sad that the participants seem to have no hope of this improving in the future. |

The codebook and an extract of a transcript with annotations are presented in Appendix 10 and 11 respectively. Once I had completed these steps for a number of transcripts, I created a coding matrix (part of which is presented in appendix 12) to visualize each code. Next, I began organising the codes into preliminary themes (step three) which were then reviewed, developed, (step four) refined and named once all data sets had been coded (step five). This involved printing the names of each code and manually organising them into themes which made sense of the dataset as a whole. Due to the nature of qualitative research, many potential ways to organise the codes into themes were considered. In order to explore various ways to organize the data into themes, I used a large sheet of paper to visualise potential ways to organise codes and consider various potential themes. This led to the development of four themes, the names of which were further refined during the writing process which involved using verbatim extracts from the data to illustrate the theme alongside analysis and interpretation (step six). The final four themes and 17 subthemes are presented alongside verbatim extracts which illustrate them in a Table of Final Themes in Appendix 13 and are discussed in full in the following chapter.

## 4.6 Research Ethics

Considering ethical research practices is essential when designing and conducting research to minimise harm to participants (Given, 2012). Historically, research has created undue harm, for example with the Tuskegee Syphilis Studies which infected Black people with syphilis and did not treat them in order to study disease progression (Given, 2012). Codes of ethics were developed in response to harmful research practices such as this, to provide vital rules to prevent further harm in research (Given, 2012). This involves considering various ethical issues, such as informed consent, confidentiality, and beneficence, which are necessary to protect research participants (Given, 2012). In order to ensure the research was conducted ethically, I obtained ethics approval from the Division of Nursing and Midwifery research ethics committee (the approval letter is presented in Appendix 14). In addition to ethical considerations required for all research with human participants, there are additional considerations when working with sensitive issues, and vulnerable groups (Adams *et al.*, 2017; Vincent, 2018a), as was the case with this research. Trans+ people have been historically mistreated within research through ethically dubious research practices (Vincent, 2018a). For example, research has been highly pathologizing of trans+ identities, has been voyeuristic or has conflated gender identity with sexuality (Staples *et al.*, 2018; Vincent, 2018a). This has led to mistrust among trans+ people when considering research, and it is important to be mindful of this history when designing and conducting research with trans+ people (Bauer *et al.*, 2019). Thus, I made efforts to build and maintain trust with trans+ participants, for example by making the aims and methods of the study clear and offering to discuss these with potential participants to ease concerns that the research would lead to harm. I also took care to use appropriate and sensitive terminology and phrasing throughout the study, and openly discussed my own gender with participants who expressed interest in this. It was also vital to consider how involving trans+ people may impact each ethical issue discussed below, for example the importance of maintaining anonymity due to the potential for harm if a participant was “outed” through their involvement in the study.

All participants were given an information sheet and a consent form (as presented in Appendix 15) in order to provide informed consent, which is a necessary step to conducting ethical research (Given, 2012; Creswell and Creswell, 2018). The information sheet details the aims of the research, the topic, the procedure, risks and benefits, and information related to data management such as how the data would be collected and stored and who will have access to it (Given, 2012; Waliman, 2017). The information sheet highlights that participation is voluntary and that the participants are able to refuse or withdraw at any point in the research (Given, 2012). Furthermore, the information sheet explains that participants may become distressed through sharing their stories, that they only have to share what they are comfortable with, that they are welcome to take breaks if needed, and can withdraw from the study if the discussions become too upsetting (Vincent, 2018a). The consent form also detailed the process of the research, including ways in which their data may be used, to ensure participants understood and consented to all aspects of being involved in the research. I also supplied participants with a support services sheet (Appendix 16) which signposts to services which provide support, including Live Through This (now OUTpatients), an LGBTQ+ cancer charity, and Mindline Trans+, an emotional and mental health support helpline run by trans+ people for trans+ people.

Additionally, I ensured confidentiality and anonymity using pseudonyms and making sure that all data was kept safe and secure using a data management plan developed by myself and my supervisors. The use of Wordpress.com for the asynchronous online focus groups provided a safe, secure, private and anonymous site, thus allowing data to be kept private, confidential and anonymous (Hancock, 2017). As above, participants were reminded not to share identifiable information within the focus groups. Also, only myself and my supervisors had access to the transcripts, some of which were slightly altered to remove potentially identifiable information about the participants.

Furthermore, steps were taken to ensure that participants felt comfortable and respected during data collection. For example, interviews were held online so participants were able to select somewhere they felt comfortable to discuss their experiences, and participants were given the choice to participate in the asynchronous focus groups, to ensure they are in the most comfortable place when sharing their experiences. However, due to the nature of the research topic I was anticipating that some participants may become upset during the interview and thus I considered how I would handle this. For example, I made sure to be supportive and understanding whilst participants were telling their stories and offered to take breaks if the participants became upset or anxious. Some participants became upset, for example by becoming frustrated or angry at their mistreatment by health services or health professionals or crying whilst discussing various experiences. I took time to show care and sensitivity during these situations, however no participant wanted to take a break and instead expressed that they shared that they were happy to have participated for the benefit of other trans+ people attending screening in the future. Some participants made jokes while telling uncomfortable stories or turned their attention to their pets or other distractions. I followed their lead, for example sharing what my own pets were currently doing, and allowed participants to return to the topic during their own time. From this, no participant ended the interview early or requested to withdraw their data afterwards.

# Chapter 5 – Findings

## Introduction

This chapter presents the findings from this PhD study to address the research question: -What are the experiences of transgender men and non-binary people when accessing and attending cervical cancer screening in Northern England? Four themes are presented using verbatim extracts from the interview and focus groups with 15 trans+ people to explore each theme and elucidate their meaning. Using the data analysis methods detailed in chapter four, the following four themes were developed and are explored below.

Theme One – How do trans+ people decide whether to attend cervical screening?

Subtheme One – Health maintenance as a motivator

Subtheme Two – “Trans people like me just get forgotten”: Feeling ignored by health systems

Subtheme Three – Worries about attending cervical screening

Subtheme Four – “Oh yeah, I put it off for a good amount of time”: Avoidance or Delaying of Screening

Theme Two – Screening is never “good” but what makes our experiences more positive or negative?

Subtheme One – Considering experiences independently is not enough: the interaction of multiple factors

Subtheme Two – All participants were worried about pain: their experiences of physical pain and discomfort

Subtheme Three – “It’s a very disempowering position to be in, isn’t it?”: Feelings of empowerment or disempowerment.

Subtheme Four – The impact of gender dysphoria or gender affirmation on experiences of screening

Subtheme Five - “It just made me feel like really out of control”: Reliving sexual trauma during cervical screening

Subtheme Six - Our needs aren’t being met: disabled trans+ experiences of screening

Subtheme Seven - Health professionals: creating comfort or discomfort

Theme Three – Relief or regret: participants thoughts and experiences following screening appointments

Subtheme One – Emotions experienced by participants following successful and unsuccessful screening appointments

Subtheme Two - The impact of screening experiences on future reattendance.

Theme Four – Making screening more manageable: recommendations for improving cervical screening for trans+ people

Subtheme One – The importance of choice; potential modifications to the procedure

Subtheme Two – Improving medical education and training

Subtheme Three – De-gendering cervical screening is good for everyone

Subtheme Four – The importance of community in coping with cervical screening

## 5.1 - Theme One – How do trans+ people decide whether to attend cervical screening?

This theme explores factors which TMNB patients consider when deciding whether to attend cervical screening, as well as issues they may face before attending screening. This includes worries, past experiences with health professionals, feeling ignored by health systems, and the desire to protect their health.

### 5.1.1 -Health Maintenance as a Motivator

Participants were knowledgeable about cervical screening, including knowing what screening is for, what it involves, what HPV is, and of the importance of cervical screening for maintaining their health. Wanting to be aware of potential health issues was an important factor in determining whether they attended screening.

Some participants described compartmentalising screening as something outside of their gender which they need to do to look after their bodies. This helps to combat the wider perception of cervical screening as a “woman’s procedure” and instead viewing it as a routine procedure for anyone with a cervix. For example:

“It's just like compartmentalised in my brain as just like a thing for my body as a machine to go and do and like get checked”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave’s use of the word “machine” suggests that Dave views CCS objectively, without subjective meanings surrounding gender, thus removing gender from both their body and the procedure. This helps to relieve discomfort surrounding screening, as a level of dysphoria is removed by reconceiving cervical screening away from societal perceptions of screening as a gendered procedure, and instead viewing screening and its impact on the body objectively. Furthermore, they described attending a cervical screening as “a bit like getting a tooth pulled out when you’re like, this isn’t very nice but it’ll, it’ll be over soon”. This further shows their removal of gender from screening as they compare it to another routine procedure which is non-gendered. It also highlights that they view screening as a procedure necessary for their health, despite the discomfort that it brings, and thus choose to attend.

Several participants described coming to a decision of whether or not to attend screening as a “risk/reward” or “cost/benefit” situation, in which they have to weigh up whether the difficulties of attending screening are worth the benefit of knowing they are not currently at risk of developing cervical cancer. Some participants concluded that it is preferable to endure screening, despite its discomforts, than to not attend and thus be unaware of a potential health issue:

“It wasn’t much of a choice really, I knew I would at some point attend and it was more about mitigating the consequences. I would rather endure the screening than not go.”

*Kit (they/them), non-binary, 25-30, focus group*

However, for other participants, the distress experienced during cervical screening was not worth knowing whether they are at risk for cervical cancer:

“It's like I'm going, I'm taking a day off work to like have my legs sawn off, you know, it kind of feels a bit like, kind of feels like that. It's just like, well, why would you do that to yourself? There might be cancer in it.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Ryan’s comparison of cervical screening to having their legs sawn off highlights their extreme aversion to cervical screening. It contrasts with Dave’s comparison of CCS to having a tooth pulled out, which is often a necessary but unpleasant procedure, showing how distressing Ryan finds this procedure. Additionally, this comparison highlights that when comparing cost/benefit, Ryan does not see the positive outcomes as outweighing the negative experiences. However, Ryan often delays screening and would rather not reattend in the future, but they find saying no to doctors incredibly difficult, so they often avoid screening for as long as possible but continue to attend.

Five participants also reported either having a family member or knowing someone with cervical cancer. Having family members who have had cervical cancer may place them at a heightened risk of developing cervical cancer, or knowing someone outside of biological family having cervical cancer and seeing them suffer with the illness were both important factors in decision making about screening. For these participants, the risk of getting cervical cancer outweighed the difficulties they faced while attending screening. For example, Ethan, who experienced extreme difficulties including physical pain, anxiety and trauma responses when attending cervical screening expressed that despite these difficulties, having family members with cancer meant that he must continue to attend screening.

“Georgia: Have you ever had any worries about going back? Have you ever considered not?

Ethan: Yeah. Um, due to the fact that there’s breast, bowel and cervical cancer sort of in the family, I can’t, I can't afford to not go back”

*Ethan (he/him), trans man, 40-45, interview*

Despite Ethan’s previous experiences of cervical screening being incredibly difficult and leading him to consider not reattending, therefore, Ethan is motivated to attend screening because he had an earlier abnormal result, and is at genetic risk for cancer. This shows that knowing someone who has had cervical cancer, whether this is biological family or otherwise, is a factor in choosing to attend cervical screening.

This subtheme highlights that being aware of potential health issues is an important contributing factor when making decisions to attend CCS. However, despite transmasculine people’s knowledge of cervical screening being important for their health, other factors may make attending screening too difficult. Additionally, it shows that transmasculine people who do attend cervical screening are not always comfortable with attending but do so despite difficulties in order to protect their health.

### 5.1.2 - “Trans people like me just get forgotten”: Feeling ignored by health systems

Many participants discussed feeling ignored and invisible within health systems, which is consistent with the wider trans+ population as outlined in Chapter One. These feelings affect trust in health services and thus impact willingness to attend screening, as transmasculine people reported fear that their needs will not be met sensitively.

Analysis revealed that some participants had a negative perception of the ability of healthcare services to care for trans people. This impacts their willingness to and discomfort with attending cervical screening due to worries about how they will be treated as a trans+ person.

“And, yeah, be nice to have a system that took medical system in general, that took trans health care, seriously, and, but obviously yeah that's a long way off."

*Robin, (they/them), transmasc non-binary, 35-40, interview*

Robin expresses both that they believe trans health care is not taken seriously, and that they have no hope for this improving in the near future. Their statement shows that they currently do not trust the health system, and also do not believe recent changes to LGBTQ+ inclusion have been successful. Distrust in the ability of the health system to care for them as a trans+ person impacts their discomfort with CCS as they have to contend with an uncomfortable and invasive procedure taking place in a system in which they already feel discomfort. This suggests a need to improve trans+ inclusion throughout health care services to improve trust in healthcare, and thus improve experience and uptake of health services such as cervical screening.

Furthermore, one participant discussed issues with health care specifically designed for trans people, and the impact this has on their trust in wider health services:

“When you read about like, you know, the kind of questions that trans people are asked by GPs and the kind of hoops that trans people have to go through to achieve, you know, the care that they need. It's like that system itself, which is designed for trans people isn't good for trans people, so how is any other system going to be trans supportive?”

*Leo, (they/them), non-binary, 30-35, interview*

Therefore, Leo has distrust and disappointment with health services designed for trans people, such as gender affirming care, and thus anticipates other health services which may not consider trans+ people. This affects Leo’s feelings of safety when accessing cervical screening, as the services which centre trans+ health are insufficient, which creates concern about health services which often do not consider trans+ people’s needs, or that trans+ people may need to access the service, such as cervical screening.

Evidence of the CCS system not providing appropriate care for trans people includes the systemic barriers reported by multiple participants. For example, participants registered as female received automatic invitations to CCS, however the majority of those registered as male did not, with the one exception being a trans man who viewed himself as “lucky”. However, he had been told that issues may arise when he receives a gender recognition certificate. Furthermore, one participant disclosed that their transfeminine friends who are registered as female with the NHS began to receive invitations to screening. The inclusion of trans women and exclusion of trans men from automatic screening invites shows that the current invitation system is not appropriate for or inclusive of trans people. Many participants shared that this disregard for trans people within health services impacts their trust in healthcare and willingness and comfort with engaging with services. Trans+ patients mistrust in healthcare is discussed throughout this thesis, such as in the previous paragraph in which Leo discusses their expectation of health professionals being unable to take care of them as a trans+ person. The thread of mistrust throughout participants’ accounts of health experiences suggests that not being trusting of health professionals/the health systems ability to provide appropriate care for trans+ people is a key element which leads to negative experiences, thus improving trust may be vital for improving experiences.

Additionally, one participant was warned by their clinician that the sample may be rejected by the lab due to having a male gender marker on their NHS. The following quote suggests that lab(s) which process cervical samples in the North of England have rejected cervical samples from transmasculine people, which shows that policies need to be updated to include trans+ people.

“The nurse was disappointed that this could be something that happens, as surely by now they should be aware trans patients exist, but she mentioned it as clearly this is something she’s sadly had to deal with before. I’ve yet to hear anything negative about the results, so suspect this was processed fine, but it was nice to have this prior warning in case I needed to arrange another appointment.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Despite disappointment at this systemic barrier, Andrew felt pleased that they had been warned about this possibility as this suggests that the health practitioner was knowledgeable of, and sensitive to, trans-specific health needs. This shows that health practitioners’ knowledge and sensitivity had a positive impact on Andrew’s experience, which is consistent across participants experiences, as discussed further in theme two.

Furthermore, Ethan disclosed that he felt ignored within CCS, and wider health care, due to information related to his health not being available in Braille.

“They've never had any information related to screening or… trans healthcare in an alternative format. And I sort of take a bit of an issue with that because I get a lot of brain fog, I've got ME and so, reading with a screen reader and synthetic speech for long periods of time affect me quite a lot and I'm a Braille reader, oh sorry we don't do Braille.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan’s experience highlights that disabled trans+ people can be ignored within screening services and wider health care due to the inability to access information relevant to them in an appropriate way. Correspondence about CCS and other health services should be made available in alternative formats in order to not exclude certain groups from information about their health.

Ryan also shared the impact of the rise in anti-trans rhetoric, as this often focuses on trans+ women whist ignoring transmasculine people. For example, Ryan stated that they feel “invisible” as a transmasculine person when accessing health services due to the focus on removing trans+ women from services and neglecting the needs of transmasculine people who may need to access them.

"Trans people like me just get forgotten even when we're talking about services that, the services that transmasculine people need because it's all, because everything is focused around kicking trans women out of everything and like trans women don't want to come here, they don't need to come here, like they're not the people asking for gynaecology and pregnancy services and things like that to become de-gendered, its transmasculine people that are saying, look, you know, we are transmasculine, we are men or we are non-binary and so, you just kind of feel very invisible”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Therefore, as described above and in Chapter One, transmasculine people often feel ignored within health services and recent media portrayal may contribute towards transmasculine people feeling increasingly ignored, which affects trust in and willingness to access health services. It is clear that the rise in anti-trans media is affecting trans+ peoples trust in receiving appropriate and sensitive healthcare.

### 5.1.3– Worries about attending cervical screening

Many participants reported various issues that contributed to delaying or avoiding accessing cervical screening. This includes worries about the screening procedure, their emotional responses to screening and health professionals’ attitudes and behaviour. A number of trans+ people also reported experiencing heightened worry in recent years due to the recent and ongoing rise in anti-trans rhetoric across the UK, as explored above and in Chapter One.

All participants reported being worried about the screening procedure. Participants shared worries about the physical pain and invasive nature of the screening procedure and referenced specifically being worried about speculum insertion. Some participants were aware that their use of testosterone caused vaginal atrophy, which made the procedure more painful and increased the likeliness of bleeding and were therefore worried both about pain and experiencing gender dysphoria from bleeding following the procedure. Worries about the pain were also exacerbated in those who had had previous negative experiences with procedures involving their genitalia. For example, G (they/them, non-binary, 25-30) felt increased anxiety following a difficult experience with the coil. The use of the speculum can also cause emotional responses such as heighten gender dysphoria, or distress in survivors of sexual trauma, which will be explored further in theme two.

The gendered environment in which screening takes place impacts transmasculine people’s feelings about attending. Andrew was worried both about existing as a visibly trans person in a waiting room and the potential responses to this, as well as making others feel uncomfortable due to their masculine presentation

“The idea of having to attend a cervical screen at a place specifically for gynaecology was terrible, as I’ve been on testosterone a number of years and have a very full beard. If I had to attend an appointment there, I likely would have really struggled to consider going. I both didn’t like the idea of being stared at in a room full of mostly cisgender women, or making them extremely uncomfortable for their own appointments by being a very masculine-presenting figure in a space they’re likely already uncomfortable being in, especially as that space they’d assumed incorrectly was meant only for women.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Andrew had a positive experience being screened in a non-gendered environment; however, they shared that had they been required to attend at a gynaecology clinic they may have struggled to do so. They pointed to the incorrect assumption of cervical screening being a procedure only for women as something that may impede their attendance due to the potential for their presence in what cisgender women assume to be a space only for other women, which may make them feel uncomfortable. Andrew also discussed the discomfort of being stared at by cisgender women as the only trans+ person there, which may be related to the rising rhetoric of creating single sex spaces which exclude trans+ women, which may impact other patients responses to them as a trans+ person in a “women’s space”. Therefore, both the procedure and the environment in which it is undertaken have an impact on transmasculine peoples’ decisions to attend screening.

All participants discussed worries about how they will be treated by health professionals, which were exacerbated among those who had experienced negative experiences in the past. For example, Jamie discussed the impact of negative experiences with health professionals both before and after coming out in health services:

“It’d definitely be easier for me to attend if I’d had more positive experiences with receiving healthcare at my practice while I identified as cis and during the period I was non-binary but hadn’t disclosed it, and if they’d given even a little bit of care when I asked to change my name and start gender-related processes.”

“Especially with my practice, I’ve had a lot of uncomfortable appointments with most of the nurses, and they refused to change my name on the system for over a year, so doing something that feels as intense as a screening feels impossible for me right now.”

*Jamie (they/them), transmascs non-binary, 25-30, focus group*

Jamie’s negative experiences within the health service have affected his trust in receiving appropriate care and willingness to attend screening appointments. Some of these experiences occurred with health professionals who would be performing the screening procedure which means Jamie anticipates further discrimination during screening, which is an invasive procedure and thus Jamie is unable to feel safe enough in their current practice to attend screening. The refusal to change their name on the health records system was also experienced by Toothless, who was able to change their name, but it kept being reverted to their deadname. Additionally, Toothless’s testosterone was repeatedly withheld by their GP and their GP refused to monitor their bloods, which is an important aspect of healthcare for those using gender affirming hormones. This is discriminatory and creates further distrust in the ability of health professionals to provide appropriate care to trans+ people, thus impeding trans+ peoples feelings of safety and willingness to attend services such as cervical screening.

A number of participants also had experiences of blatant transphobia, which creates anxiety about how they will be treated during screening. Experiencing transphobia during the invasive procedure would be significantly harder to deal with than when this is done in alternative situations, however both are damaging to trans+ people and their engagement with health services, and health outcomes.

“That was quite horrible, they, they called me he until they found out I hadn't got penis, until that point, they used the right pronouns, the instant they found out I didn't have a penis, it was she.”

*Ethan (he/him), trans man, 40-45, interview*

At a different procedure, Ethan experienced intentional misgendering[[3]](#footnote-3) when the health professionals discovered that he is trans. Experiences like this impact Ethans, and other trans+ peoples, trust in health professionals and willingness to engage in services. As above, trans+ people who have encountered transphobia in healthcare anticipate this in further health services and have heightened anxiety when considering undergoing invasive procedures such as cervical screening.

Many participants also shared worries about coming out to health professionals. Similarly to deciding whether or not to attend screening, G described coming to the decision of whether or not to come out as a “risk/benefit type situation”.

“But then again it’s like you’re choosing between two different levels of comfort... the comfort of not having to say it and kind of knowing what’s going to happen after that, or the unknown of telling someone and them, not knowing what their reactions gonna be, and not knowing whether that’s gonna make your experience better or worse”

“So, it’s kind of like a risk/benefit type of situation I guess, you’re deciding whether to take a chance and tell them and it could be a lot worse, or go, not the safe option but the option that you know the outcome of, erm, so I guess that’s why I chose that”

*G, (they/them), non-binary, 25-30, interview*

For G, coming out was anxiety provoking as they had to consider the health professionals response to their identity. G found comfort in hiding their gender because it removed any uncertainty about a negative reaction from HCPs. They felt they had to weigh up the risks of coming out with the benefits of the health professional knowing their real gender, and decided that hiding this was the easier and more comfortable route due to worries about whether this would affect how the HCP treated them. This was consistent across the data, with multiple participants reporting being so worried about the health professional’s response to their trans identity that they presented as cis women in order to avoid coming out. G related this to living in a small town, as they felt they are the only trans+ person in the area and that the health professionals working there have little to no education about trans+ inclusion.

“I live in a really rural area, there’s, you know it’s quite, it’s quite like, I wouldn’t say right wing, we have a conservative MP, it’s quite like traditional so I can’t imagine that she would meet very many people that are not just like middle aged cis women with husbands and children and then I come along and I’m like kind of pretending to be within that group of people because that’s what she’s used to”

*G, (they/them), non-binary, 25-30, interview*

G shared that they weighed up the potential benefits and risks of coming out to health professionals, and decided that it felt easier and more comfortable to not share their gender due to worries about how the practitioner would react, and the potential for being treated differently during the procedure. For example, G pointed to concerns about living in a small village as their family know their GP outside of health services so G would have to see their health professionals who potentially have a negative opinion of their gender. Additionally, G is not out to their parents and worries that telling their GP would mean this information is passed onto their family without their consent. G contrasts this with their experiences of living and accessing health care in a large city, as discussed further in theme two subtheme seven, in which health professionals had increased education on trans+ health and had cared for many queer and trans patients which improved the health professionals understanding and experience of caring for LGBTQ+ patients. G shared that this was helped to reduce their anxiety as they knew their health professional would be considerate to them as a trans+ person, and were able to receive better health care there. However, disclosing their identity felt difficult in their hometown due to the perception that they would not be as trans+ inclusive, or that they may secretly harbour negative opinions about trans+ people, which would impact the outcome of the procedure. This shows that the location of health services may impact trans+ peoples’ willingness to attend screening.

As above, trans+ people may worry about health professionals secretly having negative opinions about trans+ people. This can create anxiety about HCPs responses to their identities, which has led some participants to hiding their gender:

“I think, it's just never knowing truly, whether that person, you know harbours some sort of not, maybe not to the extent of like homophobia or transphobia but like some perception that could change the way that they might possibly treat you even though they're not supposed to.”

*L, (they/them), agender and outside of the gender binary, 25-30, interview*

L expressed that the health professionals they have encountered have always been nice, kind and professional, however they do not come out to them due to the fear that despite their kind presentation, they may secretly harbour negative opinions towards queer people and thus change the way they treat L, both during screening and within general health services. This highlights the need for health professionals to be outwardly inclusive in order to indicate that they are queer friendly and reduce anxieties such as this.

This idea is further developed by G who shares that even health professionals with good intentions may cause harm due to the lack of education on providing appropriate care for trans+ people:

“When you don’t know how informed that persons going to be, how they’re going to respond, you know even the nicest person in the world might be so uninformed that it then begins to take over.”

*G, (they/them), non-binary, 25-30, interview*

G reported an additional layer of anxiety related to coming out to HCPs, as even if their response to trans identities is positive, they may not have sufficient education on trans+ health care and thus questions about gender/sexuality, or unintentional transphobia may make this experience worse. This highlights the need for improving trans+ health education in order to create feelings of safety and inclusion within healthcare.

This anxiety can be especially prominent for non-binary people, who often have to contend with explaining what “non-binary” itself means due to a lack of LGBTQ+ education. For example:

“The GP I spoke to is honestly like, not like transphobic but just so bamboozled by the idea of someone who could be trans but not like, in a very binary sense and so it's not like a space that has like filled me with loads of, like in my other interactions with them as health care providers I haven't felt like massively comfortable erm, you know, as a trans person it's almost just like never mind, I'll just, I'll just be someone else while I'm here.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave disclosed that their GP does not understand what it means to be trans outside of binary genders (referring to being a trans man or trans woman). This, along with other interactions, has made Dave feel uncomfortable in their health settings, which are where their CCS takes place, and thus feels like they have to pretend to be “someone else”. Other participants shared that they have had to explain what being non-binary means, with both positive and negative outcomes. This adds an extra layer of anxiety as non-binary people have to contend with potential negative reactions to their trans identity, as well as being the first person to explain what being non-binary means and whether the HCP will understand and respect this.

Ryan shared a small amount of hope for the improvement of understanding of non-binary identities and health needs. For them, this would require non-binary people being included in the gender recognition act, so that non-binary can be recognised as a legal gender, as well as the need for a societal shift to include non-binary genders.

“No idea if this is gonna happen, but, you know, hopefully with kind of if things like better recognition or, you know, being included as part of the gender recognition acts and stuff like that, like, there's a whole societal shift that needs to, that's happening, but needs to keep on happening and it's not just the NHS uh, unfortunately”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Ryan shared that they believe this is starting to happen, however in their experience the shift is not happening within the NHS. Therefore, further education and understanding of non-binary identities is needed in order to improve cervical screening experiences for all trans+ people, not just trans men.

TMNB also experience concern about health practitioners’ responses to their medical and/or social transition. Jamie disclosed that their medical records not currently containing information about their gender being a deterrent from accessing screening as they hope that an explicit mention of their trans identity and intention to transition will mean health practitioners take their identity more seriously and are sensitive to this. This is reflected in the testimony of other participants who share that some health practitioners treat them as cis women and ignore their trans identity. However, Jamie also shares concern that being explicitly transgender may impact their ability to access screening, with reference to potentially facing systemic barriers discussed in Chapter One.

“I’m considering waiting until I’ve started T… (testosterone) so that it’s on my record and more explicit that I’m not a cis woman, in the hopes that it at least makes them more mindful. But at the same time am worried that being an explicitly transgender person trying to access a screening would be more difficult process and have me face more issues, if that makes sense.”

*Jamie (they/them), transmascs non-binary, 25-30, focus group*

Furthermore, trans+ people worry about how the use of testosterone and its impact on their body will affect health practitioners’ behaviours. Both Toothless and Blue discuss worries about feeling judged by health professionals or being treated differently as a result of this.

“I am a bit nervous now that I'm on T (testosterone) because obviously you get like lower growth and stuff and like, I wonder like, what they think.”

*Toothless, (he/they), trans man, 25-30, interview*

“If all goes well, by the next time I attend I will be taking testosterone, which makes me feel even more nervous (will practitioners treat me differently? Will the procedure be more difficult/painful?)”

*Blue, (they/them), non-binary, 30-35, focus group*

Toothless shared that they feel anxious about how practitioners will respond to their body due to lower growth, which refers to the increased size of the clitoris from testosterone use. Health practitioners may not be used to caring for trans people, or aware of different trans bodies, and thus Toothless worries about the response that health practitioners will have to this change. Blue also expressed worry that the procedure may be more painful due to the use of testosterone, which was a worry shared by multiple participants and experienced by those using testosterone. This shows that despite the euphoria or affirmation of using gender affirming care, trans+ people also experience worries about how the use of gender affirming hormones may impact their treatment within health services such as CCS, and thus experience an additional layer of anxiety when deciding to attend screening.

Additionally, some participants referenced experiencing increased discomfort about cervical screening due to trans+ rights, attitudes towards trans people and the media portrayal of trans+ people getting worse in the UK. This has led to increased fear of being visibly trans+ in public, as well as increased worries about how providers and patients will respond to their gender identity.

### 5.1.4 – “Oh yeah, I put it off for a good amount of time”: Avoidance or Delaying of Screening

A number of participants reported delaying screening, not attending as regularly as they should, or avoiding screening. This includes deciding to attend screening but not feeling ready to for various reasons, and avoiding accessing other health services due to not wanting to be pushed to attend screening.

One participant had not attended screening but intended to due to their knowledge of the importance of the service. However, other factors had made it too difficult to attend:

“I know that the screening is incredibly important to do, so I definitely intend to attend a screening at some point. Right now, I’m concerned about a lack of understanding around my gender dysphoria and discomfort around screening from whoever would be doing it, especially because I’d probably have to accept misgendering and dysphoria during a physically intense practice. I’m just not in the headspace for it right now.”

*Jamie (they/them), transmascs non-binary, 25-30, focus group*

Jamie referenced their understanding of the importance of screening, however they described needing to be in the right headspace to attend cervical screening in order to cope with the dysphoria and discomfort, and lack of understanding of trans+ issues that they expect from health professionals. “Headspace” referred to having good enough mental health and feeling affirmed in their gender in order to cope with anticipated insensitive behaviour with regards to being trans, such as misgendering, and increased dysphoria during the procedure. Jamie feels they are currently not in a place to experience this, but if their mental health and feelings of being affirmed improve they will access screening and cope with the procedure better than they currently would. This shows that despite knowledge of the importance of screening, other factors which may make attending screening more difficult can result in delaying or avoiding cervical screening.

Additionally, some participants reported delaying cervical screening due to discomfort with the procedure, including delaying reattendance. Transmasculine patients have to deal with the invasive nature of the screening procedure, as well as trans specific issues which make screening more difficult. For Jack, this resulted in delaying screening:

“Oh yeah, I put it off for a good amount of time. Yeah. Yeah, just because the whole experience may be really uncomfortable, the thought of having to do that being uncomfortable in my own body with someone who sees you as a woman and don't know whether they're going to be careful about things.”

*Jack, (they/he), transmasculine non-binary, 25-30, interview*

Jack finds the screening procedure uncomfortable, and this is exacerbated due to feeling uncomfortable in their body, the procedure being done by a health professional who he expects to view them as a woman, and being unsure of the health professionals’ attitude towards trans people or how they will behave. The data highlights that many health professionals’ attitudes and behaviour affect experiences of CCS, and future reattendance, which will be explored more in theme two subtheme seven. These issues mean that Jack, and other transmasculine people, delay screening.

Finally, the discomfort of talking about cervical screening or being pushed to attend can cause transmasculine people to avoid other health services. For example, a distressing experience of being asked about screening has led to Ryan avoiding attending their asthma reviews to avoid a repeat of this situation:

“The asthma nurse like brought it up, she was like ‘oh I, there’s a thing on your record that says you need to go for a smear test’ and I kind of tried to talk to her about why I don't like it, and why I don't go and she just… it was ah, it was awful [4 second pause] so then I stopped going to my asthma reviews because I really don’t want to talk to the asthma nurse anymore, like if she asks me about the smear test again, I can't do it. I'm stuck there because she's like, in the middle of writing my prescription for my inhaler so I can't just like, get out”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview,*

Ryan shared that the distress they felt while discussing cervical screening made them want to leave, however they weren’t able to as they needed their inhaler, so they felt trapped having to talk about something which they find incredibly distressing to discuss. The asthma nurse also asked about gender and sexual practices, which Ryan found uncomfortable due to not being prepared to have this discussion. This experience has left them feeling too worried to reattend asthma reviews in case it happens again, and thus the distress relating to cervical cancer screening has impacted accessing a different health service.

In conclusion, transmasculine people are aware of the importance of cervical screening for their health, however other factors can make it difficult to attend which may result in delaying or deciding not to attend screening. Transmasculine people have to weigh up the benefits of screening with the negative aspects in order to decide whether to take part in the service. Some trans+ people choose to go to screening due to their desire to protect their health, however, the interaction of multiple issues discussed above can make it too difficult for some trans+ people to attend screening, resulting in delaying or avoidance.

## Theme Two – Screening is never “good” but what makes our experiences more positive or negative?

All participants reported emotional, physical and/or psychological pain as a result of cervical screening. These experiences were exacerbated by different factors, which will be explored within this theme. First is a discussion of issues relating to cervical screening including the interaction of multiple factors, gender dysphoria, physical pain and sexual trauma, followed by experiences relating to the healthcare system, such as health professionals’ behaviours and systemic barriers.

### 5.2.1 Considering experiences independently is not enough: the interaction of multiple factors

Whilst the following theme discusses issues independently, it is important to note that issues which influence participants experiences of cervical screening are often interlinked. Participants reported multiple interlacing factors which have a culminative effect on their experiences of cervical screening, which often leads to worse experiences of screening including feeling shame, physical and emotional discomfort, and feeling disenfranchised.

This is evidenced in the data by multiple participants, including Ryan and Ethan who discussed multiple issues which intersect to create a difficult experience. Ethan disclosed that his difficulties with cervical screening begin from the arrival of the invitation letter. For example, Ethan requires to be screened at a hospital rather than GP, however Ethan receives a letter inviting him to be screened at the GP. This means Ethan must attend a GP appointment, explain that he needs a referral to attend screening at the hospital and wait for a second letter and arrange for someone to attend with him, all before entering the appointment. Further, within the appointment Ethan must contend with gender dysphoria, feeling like they stand out in a room full of cis women and feeling judged by this. He also experiences physical pain, issues arising from sexual trauma, anxiety about the procedure and worries about how the health professional will treat him as a trans and disabled patient undergoing a vulnerable procedure. This shows that Ethan experiences a range of issues relating to cervical screening which interact to produce a negative experience.

“I've got to make an appointment with the GP, explain I need the referral, wait for the second letter from colposcopy to drop on the doorstep, arrange for my mum or a carer to accompany me, get stared at by all the women in maternity, even if they're not it's how I feel, and just go through all that, all that process, even if the screener is pretty positive, once I get into the room, it's all the issues around it.”

*Ethan, (he/him), trans man, 40-45, interview*

Further, Ryan stated that they find the procedure too painful, require to be sedated, require their partner to attend with them which involves their partner taking time off work and telling her employers that they need to help Ryan with their cervical screening appointment, experience gender dysphoria and do not feel able to provide informed consent to the procedure, which they discussed feeling guilt about. As a result, Ryan shared that they feel like a “special case” and worry about judgement from the health professionals due to finding screening so difficult. They feel embarrassed and ashamed to have to be a “special case”, meaning they require additional changes in order to undergo the procedure, as they feel screening is a basic procedure that they should be able to undergo. Their embarrassment is also worsened by cisgender women friends who have expressed judgement and have not been able to understand why Ryan struggles with screening because they are able to undergo the procedure with ease.

“And yeah, and I kind of hate that I have to be like a special case.”

“I always worry that they're thinking like, oh my god, this person's like such a baby, like you know, you're in your 30’s and you can't handle this very basic thing. And it's not basic. It's awful, it's awful.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Through an intersectional lens, it is clear to see that Ryans identity as both a trans+ and autistic person collide and impact their experience of screening. Ryan feels uncomfortable that they have to be a “special case” due to factors arising from their being trans+ and autistic, such as gender dysphoria and sensory overwhelm. These factors intersect to create layers of discomfort for Ryan, which intersect and contribute to a difficult experience which is different from those of a person who is only trans+ or autistic. Thus, trans+ peoples experiences of screening cannot be fully understood by considering factors independently. Therefore, the factors discussed in this theme must not be considered independently, but as factors which are experienced at the same time and intersect to produce an, often negative, experience of cervical screening.

### 5.2.2 All participants were worried about pain: their experiences of physical pain and discomfort

All participants discussed being worried about experiencing physical pain. Further, 13/14 of those who have attended screening experienced physical pain or discomfort during their screening appointment. Only one participant reported experiencing no pain during the procedure, and multiple participants stopped the procedure due to physical pain; some participants were able to try again and successfully provide a sample however others were unable to do so. Additionally, two participants required sedation in order to undergo CCS due to previous experiences of pain, including gas and air and general anaesthetic. This highlights the severity of the pain that some trans+ participants experience. For example, Leo shared that the pain they experienced during CCS was so severe that the procedure had to be abandoned multiple times:

“It would be too painful for me to like, continue or whatever because, because [in their diary] it's like, yeah, I've just said, it's like so much, so painful. Yeah, I couldn’t will myself to go through it”

*Leo, (they/them), non-binary, 30-35, interview*

Leo was determined to undergo screening, as discussed in theme three, however they found the pain too difficult to overcome and halted the appointment multiple times. This highlights the severity of the pain as Leo was very willing to undergo CCS but could not continue.

The pain endured during CCS can also continue following the appointment. For example, G stated that they were “in pain for at least a day and there was some bleeding”. G shared that they believe their nervousness about undergoing the procedure led to an increase in their pain and that they struggled both with the procedure, and with the pain following cervical screening. Additionally, bleeding following cervical screening can be a reminder of menstruation, which can cause dysphoria and therefore experiencing pain and bleeding following CCS can be both physically and emotionally uncomfortable.

Furthermore, trans+ people who use testosterone may experience increased pain due to the effect of the hormone, such as the drying or thinning of vaginal walls. Ethan shared that his experience of testosterone makes speculum insertion painful, and other participants also expressed worry about their pain being increased once they begin gender affirming care due to the effects of hormones.

“Being on testosterone actually makes me incredibly dry in between my legs, so having speculum inserted can be even more painful and it can be quite difficult, trying to explain that to some doctors that are not sort of gender aware, so it it's great if you get somebody that says, oh I see you’re on testosterone, we can use some lubricants but that's very rarely the case.”

*Ethan (he/him), trans man, 40-45, interview*

As above, Ethan finds that testosterone use has made cervical cancer screening more painful for him than CCS appointments before starting gender affirming care. Ethan shared that explaining the effects of testosterone and the impact on his pain during CCS can be difficult when the health professionals are not already aware of this. However, some health professionals have been aware of the effects of testosterone and have offered more lubricant, which reduces pain and also shows Ethan that they are aware of trans+ issues and thus helps him to feel safe and secure with those HCPs. Unfortunately, in Ethans experience this has rarely been the case, which shows a need for improving knowledge about the effects of testosterone on pain levels and modifications which can be made to reduce pain.

Ryan, who requires a sedative to undergo screening due to the pain, shared that whilst the sedative reduces pain, it does not eliminate pain and thus the procedure continues to be uncomfortable but “doable”. Additionally, they shared that other issues arise from the use of a sedative. For example, their partner has to go to the appointment with them in order to take them home safely, which requires them taking time off work and thus interrupting not only Ryans day but also their partners, which Ryan disclosed they felt guilty about. Additionally, Ryan feels embarrassed that they find screening so difficult that they require sedation, which shows that although sedation can reduce physical pain, it may lead to further emotional discomfort.

Only one participant, Bruce, did not experience pain during the procedure. Bruce had been nervous about pain but was pleasantly surprised that they did not experience discomfort:

“I was then told that they were now going to swab the cervix and I was shown the swab – again I could hear the GP instructing how to do this and for this, I felt nothing, no pain or sensation at all.”

“Once I did it, I did think “oh that wasn’t so bad!”. BUT I know this is my unique experience and I had built up my confidence to get there.”

*Bruce, (they/them), trans non-binary, 35-40, focus group*

Bruce shared that they believed their experience would’ve been significantly worse prior to being affirmed in their gender, as discussed in theme two subtheme four. Other participants shared that being anxious worsened their pain, and therefore the calmness that Bruce was able to achieve from building their confidence and feelings of being affirmed may have led to them not experiencing pain or any sensation during the procedure. Additionally, the procedure was explained to Bruce throughout the appointment, including being asked if it was okay to continue to the next step within the procedure.

Andrew also had a positive experience, despite experiencing pain during the procedure. Andrew had been worried about physical pain during screening, especially due to being asexual (which refers to not experiencing sexual attraction) and having never had sex. Similar worries were also shared by Toothless, who is also asexual. Thus, for Andrew and Toothless, concerns about pain are impacted by both their trans+ and asexual identity, elements of which intersect to impact anxiety about pain, and potentially actual experiences of pain. For example, Andrew shared worries about pain due to both being a testosterone user, and being asexual and thus not engaging in penetration, both of which can impact pain. The intersection of these identities creates a different experience than that which may be experienced by an allosexual trans+ person, or an asexual cisgender person. Andrew experienced pain during their appointment, but felt comforted by the nurses response to their sexuality and anxiety about physical pain.

“I felt extremely awkward during this, and it was rather painful – especially as I’m an asexual and have never been sexually active – but the nurse was honestly fantastic in being a comfort about it.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

After having a positive first experience, Andrew was less anxious about attending her second appointment, during which “there was even less pain than the first, possibly because I’d been so relaxed, and it was far less stressful than I was expecting it to be”. This shows that reducing nervousness can lead to reduced physical pain, which suggests that making changes to make CCS less stressful for TMNB may also reduce physical pain.

### 5.2.3 “It’s a very disempowering position to be in, isn’t it?”: Feelings of empowerment or disempowerment.

All participants reported experiencing some emotional discomfort during cervical screening. For example, the majority of participants reported being nervous before attending cervical screening, especially for their first appointment. Further, some participants disclosed their concern about being embarrassed, however all felt less embarrassed than they thought they would. Participants also discussed experiencing gender dysphoria, feeling disempowered, and feeling violated by the procedure, for example:

“I don’t know, like it’s it’s a very disempowering position to be in, isn’t it? Because you’re like no, you’ve got no clue what’s going on sort of at the other end of your body because you just can’t see anything, you know.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave reported feeling anxious and disempowered during the screening procedure as they could not see what was happening to their body, and the health professionals were not sharing information about what they were doing or how the procedure was going. Dave felt disempowered as a result of this, as something was happening to their body in an intimate and uncomfortable way and they had no control over this and were thus experiencing a disconnect between their mind and body. This contrasts with Andrew’s and Bruce’s experiences of feeling more in control of the procedure due to having this explained and being asked before continuing at every step. This shows that open communication between the patient and provider may help to reduce anxiety and feelings of disempowerment, and thus lead to a more positive experience.

For Ryan, their feelings of disempowerment connected to them not feeling like they had a choice in whether or not to attend cervical screening as a result of pressure to attend, which came from friends, family, peers and medical professionals. Ryan has had multiple negative experiences of CCS and stated that they would prefer not to attend, however under pressure from medical professionals they feel like they are unable to say no.

“I don't feel like it's fully informed consent going for the smear test, cos there's a bit, because there's a bit of coercion isn't there, with, from the pressure and stuff like this and I said like. So there's a kind of I think that's, that's a big part of it.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

For Ryan, a “big part” of discomfort with the procedure came from not feeling like they had consented to being there, due to the myriad of reasons they would prefer not to attend, however feeling like they had little choice in this. The term “consent” being used in relation to a procedure involving genitals highlights how distressing Ryan finds this procedure, and their perceived lack of choice in attending.

Further, Jack shared that the CCS procedure feels “violating” due to the pain caused by the speculum, and not wanting to undergo the procedure. The term “violated” highlights the severe discomfort and pain that Jack feels during CCS, and that Jack, as well as Ryan, feel uncomfortable attending screening but feel like they have little choice in this.

“Really weird way to describe it but a little bit violated in a way, just because it doesn't feel, I don't know, feels a bit weird, it’s really painful, it’s something I don’t want to do. Yeah.”

*Jack, (they/he), transmasculine non-binary, 25-30, interview*

### 5.2.4 The impact of gender dysphoria or gender affirmation on experiences of screening

Additionally, all participants discussed experiencing gender dysphoria, and most participants shared that their dysphoria was heightened at their screening appointment. Participants disclosed that dysphoria made screening incredibly difficult due to the emotional distress they experienced as a result of the reminder of areas of their body that they felt did not align with their gender:

“I felt very out of place, very much like I did not belong. Like it was a failing of my body that I was here having to do this.”

“On that occasion it was more like a sense of wrongness, that my body was not my own and like a constant under the skin itch feeling. Not finding any joy in queerness, just general distress at the disconnect between my identity and physical human shell.”

*Kit (they/them), non-binary, 25-30, focus group*

Kit disclosed feelings of “failure” and “wrongness” for both having to attend screening, and how their body felt during screening. The disconnect between their identity, including their gender and sense of self, and their physical body was heightened as a result of attending screening. This sentiment was shared by multiple participants when discussing gender dysphoria and CCS.

Gender dysphoria can be incredibly debilitating, as shared by Ryan who experiences such severe dysphoria that they suggested that a benefit of having cancer would be that they may have to undergo a hysterectomy, which would alleviate their dysphoria.

“I don’t particularly have like dysphoria around like genitalia or anything like that by definitely kind of have dysphoria on the fact that there's like a thing in here that I, I don't want it's a bit like well if I’ve got cancer in it you'd have to take it out and maybe that'd be fair enough”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Ryan shared the difficulty of accessing gender affirming care, such as a hysterectomy, in the UK due to the long waiting times on the NHS or the option of using expensive private care. However, this care would alleviate Ryans dysphoria, as well as meaning they would no longer have to undergo CCS. Therefore, Ryan shared that the CCS procedure finding cancer and leading to the removal of reproductive organs which cause them dysphoria would be “fair enough”, which suggests that this would be a benefit of the diagnosis. This highlights how severe Ryans experience of gender dysphoria is, and how it impacts on their daily life. Additionally, this highlights the discomfort of navigating a health care system which is inappropriately set up on the basis of binary gender.

The environment in which CCS took place can also lead to heightened gender dysphoria. Participants who attended CCS at a hospital were often faced with gendered environments such as maternity wards, which tended to be painted pink and were very woman or mother and baby focused, which created dysphoria among participants who felt out of place and like they did not belong there.

“The ward was named ‘The Women’s Unit’, which made me so dysphoric I almost didn’t turn up to the appointment.”

*Blue, (they/them), non-binary, 30-35, focus group*

The term “The Women’s Unit” caused intense dysphoria for Blue, who struggled to attend this appointment due to the dysphoria and discomfort this name caused. The name “women’s unit” ignores that transmasculine people may need to access services which health systems deem only required by women, such as cervical screening or maternity services, which highlights to trans+ people that the health systems do not consider their needs. This environment also meant that the participants were the only non-women on the ward, which often outed them within waiting rooms and caused anxiety about being visibly trans.

Further, Ethan, who is blind and thus unable to see the gendered environment, shared that he experienced heightened dysphoria and self-consciousness within the maternity ward due to being the only man in the room.

“[Being in the gynae ward] puts my dysphoria through the roof. Because even… though I am, even though I'm totally blind, I subconsciously feel like I'm being stared at. So, like, I feel like people are going “why is he here?”

“There was one visit that erm, I was in the maternity unit and this little child said to the person they're with, “mommy why is that man here? Men can't have babies.” And while some people in the waiting room giggled, I just wanted the floor to drop off.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan shared that he feels uncomfortable in the waiting rooms of maternity units due to feeling stared at and questioned as to why they are there. Ethan’s use of the phrase “I just wanted the floor to drop off” highlights the severe discomfort felt from being placed in a ward which is explicitly non-inclusive of trans+ people.

Additionally, some participants discussed that the procedure also caused more intense gender dysphoria, such as Toothless who disclosed that the insertion of anything is dysphoria-inducing and distressing for them, and thus the use of the speculum heightened their dysphoria. Additionally, multiple participants shared that health professionals’ attitudes and behaviour can impact their experience of gender dysphoria, which is explored more in theme two subtheme four.

In contrast, some participants stated that as they felt more affirmed within their gender, CCS became easier. Feeling more affirmed came as a result of furthering their social or medical transition, such as starting gender affirming care. For some participants, feeling more affirmed in their daily life meant that CCS did not have as much of an impact on how they felt about their body:

“I felt ok but this was largely due to where I was with my mental health and my gender affirmation at that point….prior to this affirmation, I know that I actively avoided attending the screenings as I was uncomfortable with the thought of the physical process and the vulnerability I experienced”

*Bruce, (they/them), trans non-binary, 35-40, focus group*

For Bruce, being in a good space with regards to their mental health and gender affirmation was paramount to being able to access and attend CCS, and to feel “ok” during the appointment. Prior to this, Bruce believed they would have had a much more negative experience and thus avoided screening until they were able to be certain that the appointment would not be too distressing. This highlights the necessity for some trans+ people to feel comfortable in themselves, their gender and their bodies to attend screening.

In contrast, Ryan shared that as they furthered their transition, they began feeling more uncomfortable with screening as it began to feel more feminine than things they were used to experiencing in their everyday life, and thus brought discomfort.

“In between my first time and second I did do my name change and that's when I kind of like socially transitioned. and so like now I kind of feel a bit awkward like going because the first time I kind of was still kind of like I'm kind of non-binary but like pretending to be a cis woman sometimes it's like, okay, you know, I mean, like that kind of like like I'll do it when I have to but otherwise, I don't or as like now it's definitely like no. I'm definitely not a cis woman so it like the more the longer time goes on, like, the more, the kind of, like, feminineness of it comes across”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

For Ryan, transition helps them to feel more affirmed in themselves and their gender, however the feeling of affirmation is reduced during CCS. Changing their name to a more masculine name on their NHS records means that it is obvious to HCPs that they are not a cis woman, which prior to their name change they were able to present as for ease during the appointment. Since being more affirmed in their gender as a result of social transition, Ryan is able to experience gender euphoria of being seen as their true self and feels uncomfortable when this is not affirmed, for example during CCS. As a result, Ryan focuses on the femininity associated with cervical screening and feels more uncomfortable and dysphoric that they have to attend. Thus, as they further their transition and become used to being viewed as non-binary in their everyday life, engaging in activities such as CCS which feel feminine have become more difficult as a reminder of their sex assigned at birth.

### 5.2.5 “It just made me feel like really out of control”: Reliving sexual trauma during cervical screening

The invasive nature of the procedure also made screening more difficult for survivors of sexual trauma. The use of the speculum was especially triggering for a number of participants and led them to feel out of control of what is happening to their body, which was a reminder of the sexual assaults.

“It just made me feel like really out of control. Just like I had no say over what was gonna happen. Yeah. And especially for like, I'm speaking for myself here, but I'm sure it was the same for other people who've had like sexual assault experiences in the past, that can just feel a little bit like reliving it.”

*Jack, (they/he), transmasculine non-binary, 25-30, interview*

For Jack, attending CCS felt like reliving their sexual assault, due to the act of speculum insertion into the vagina, and the lack of control during the procedure. This sentiment was discussed by other participants who had similar past experiences. This suggests that helping patients to feel more in control during screening, which is an important element of providing trauma informed care as discussed in theme four, may help to reduce distress related to past sexual trauma.

Another participant who struggled with cervical screening due to being a survivor of sexual trauma shared that the health professional’s behaviour can impact their feelings of safety at cervical screening. Ethan had a history of childhood sexual abuse and found CCS to be incredibly triggering and distressing due to the trauma, along with issues related to his trans identity and disabilities. Ethan told the health professional before each procedure that he was a survivor of childhood sexual abuse, in the hope that the HCPs would be more sensitive and gentle, and thus the doctor in the following situation was aware of this.

“E: I lashed out with an arm and the punched him in the, in the balls [both laugh]… Yeah. He got the, got the speculum inside me and I said look you need to take that out, it really hurts, and he said well I just need to, his words were, I just need to crank it open a bit more and I'll be done in a minute, and I just must have seen red and my arm just went”

*Ethan, (he/him), trans man, 40-45, interview*

Due to Ethan’s blindness, the punch unintentionally landed in an unfortunate place. Following this, Ethan consented to be sedated for future screening appointments. Ethan discussed feeling like this was in order to keep the health professionals safe from him, rather than to reduce the psychological and emotional pain he felt due to being a survivor and as a result of the health professionals’ actions. This also impacted Ethans trust in being provided appropriate care with regards to his trauma in the future, and thus his trust in HCPs. The experiences of participants who have experienced sexual trauma highlights the need for HCPs to undergo trauma informed care training.

### 5.2.6 Our needs aren’t being met: disabled trans+ experiences of screening

Having a disability may also make screening more difficult to attend. Within this study, 13/15 participants described themselves as having a disability and some shared the impact this has on CCS. For example, Robin, who used to have vaginismus[[4]](#footnote-4), found CCS extremely painful. CCS providers should have knowledge of vaginismus in order to signpost people who may have this condition to treatment or to modify the procedure to make it less painful, such as the recommendations discussed in theme four. Additionally, Leo suffers from a chronic illness which makes CCS incredibly painful and therefore requires changes to the procedure to undergo it. Prior to their diagnosis and treatment, Leo was not able to undergo a successful screening due to the pain. The implications of a painful CCS and potential changes that can be made in order to meet the needs of people who are trans and/or disabled are discussed in theme four.

Ethan disclosed numerous negative experiences which arose due to his disability, both within cervical screening and within wider healthcare. Ethan shared a deep frustration that when he felt distress due to the impact of his sexual trauma on screening, health professionals ignored that he was feeling triggered and instead viewed it as being a behaviour from his disability. This left Ethan with no reassurance or comfort whilst feeling emotional distress, and instead health professionals belittled his trauma by referring to him as being a “naughty girl”, thus patronising him as he was an adult. Further, a number of health professionals had spoken only to Ethan’s mum or carer, despite Ethan being verbal and both able and wanting to speak for himself. Ethan found this frustrating as he wanted his own voice to be heard but felt that due to being a wheelchair user he was viewed as being incapable of communicating.

“Um, when, before I came out as trans um, some of them were quite sort of patronising with me being blind, erm… if I sort of tensed up they put it down some to me being blind, me being sort of as one of them, put it ‘a naughty girl’”

“I think the most annoying thing is… when my mom first took me in to see the gynaecologist, I was a teenager and, I'll, I'll use my, I'll use my current name, but I'm talking sort of sort of past tense, he looked directly at my mum and said “so what are [Ethan’s] periods?, how much blood does [Ethan] lose on a pad?” and I kept trying to answer my questions and this doctor kept saying “how much pain does [Ethan] get when [Ethan] has his period?” My mum got up and she actually walked out [laughs] the nurse came running out after her begging her to come back in, and after that, he actually started to talk to me. But he was, he was a bit of a strange doctor.”

*Ethan, (he/him), trans man, 40-45, interview*

This alienation of Ethan due to his disabilities, compounded with Ethan’s experiences of transphobia within health systems, has greatly impacted Ethans trust in health professionals due to experiences of ableism and transphobia, which seem to have been both intentional and unintentional at different circumstances.

Finally, just over half of the participants (8/15) shared that they were neurodivergent, including conditions such as autism, ADHD and borderline personality disorder. Being neurodivergent affected some participants experiences of cervical screening. For example, Ryan disclosed that being autistic makes any hospital appointment, including CCS, incredibly difficult:

Ryan experienced severe pain during screening procedures and required hospital appointments so they can be sedated for the procedure. Although this alleviated physical pain, Ryan continued to experience emotional distress including that related to gender dysphoria, as well as issues that were heightened due to being autistic. Therefore, their worries about the procedure were made worse by the environment their appointments take place in.

“Hospitals in general are a bit of a sensory overload ‘cos they're so bright and there's so many people, they've always got the TV on. And it's distracting and you can't like, put your headphones on because you miss people yelling at you… so I have to sit there with my headphones off, it just already awful”

“Like you know being autistic, like going to hospitals is like hell anyway but there's not really, like they should be more things for that, you know, they should be, I should be able to wait in a quiet room or a room that's not filled with like “so you're having a baby” posters and things like that, you know, there’s a quiet room where they let you sit to like let some of the gas and air like wear off. So they they put me in it so after it's done I get like a nice dark room with an armchair to like, and then I can stay there until I feel that I'm able to leave and so that's nice.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

It is clear from the quotation above that for autistic participants, attending hospital or GP appointments can feel overwhelming due to sensory issues relating to the environments. Usually, Ryan copes with sensory issues by wearing headphones but they are unable to do this due to potentially missing their name being called, therefore whilst waiting for their appointment they already feel overwhelmed by the environment in a way non-related to the procedure. This, along with discomfort with the procedure, worries about how they will be treated as a trans person, and the gendered environment of hospitals makes screening incredibly difficult for Ryan due to multiple interlacing factors which produce a negative experience. Additionally, Ryan disclosed that they felt “guilty” about struggling with the procedure as this meant that their partner had to attend with them, which involved taking time off work. For Ryan, the interaction of multiple factors made it incredibly difficult to continue attending, and they often delayed this.

### 5.2.7 – Health professionals: creating comfort or discomfort

All participants reported that their experiences of cervical screening were influenced by the health professionals. This includes health professionals’ attitudes, behaviour and knowledge of trans+ issues. This subtheme will explore how these factors affect trans and non-binary peoples’ experiences of cervical cancer screening.

The findings highlight that health professionals’ attitudes and behaviours towards trans+ participants can impact their experience of cervical screening. For example, participants reported that attending cervical screening with a health provider who was knowledgeable about trans+ issues helped them to have a more positive experience, however those who felt their health provider did not have sufficient knowledge had a more negative experience. For example, Andrew disclosed that both health professionals who have undertaken his screening appointments have been knowledgeable about trans+ health, and that this helped them to feel safe and supported during the procedure.

“Both nurses I’ve had during my two screenings have been absolutely phenomenal, knowing beforehand what difficulties I might have during my screen as a trans man who has been on testosterone for years, and how to help mitigate them. I suspect the GP I’ve been attending for years either have several trans patients (considering both myself and my partner are attending the clinic actively as trans men) that they listen to, or have had really good transgender training, as the nurses knew more about how my body would react to the screen than even I was aware!”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Andrew described feeling comforted by the health professionals as they had great knowledge about providing cervical screenings to trans+ people and were able to share information with her. This helped Andrew to feel safe and cared for, which was important in maintaining their calmness. Andrew also shared having a positive experience with the health professional on their first screening exam helped him to feel less anxious about attending her second appointment, which in turn helped to reduce the physical discomfort Andrew felt at the second appointment due to being calmer and less anxious. This shows that health professionals’ knowledge of cervical screening for trans+ people and willingness to share potential difficulties and ways to mitigate them can create more positive experiences of screening, which may both reduce anxiety about, and improve rates of, future uptake.

However, many participants reported that the health professionals who undertook their CCS were less knowledgeable about trans+ health, which impacted their feelings of safety within the appointment. For example, Ethan attended a cervical screening appointment in which the gynaecologist was unaware that trans men require cervical screening and was confused as to why a man may need to attend the gynaecology clinic.

“I had one gynaecologist that looked at my paperwork erm and said “why have they sent a male to my clinic?” and I said “well, I need a smear” “oh, but I thought you might have had a penis or something”. He seemed to have the assumption that all men are gonna have a penis and that's obviously not the case.”

*Ethan, (he/him), trans man, 40-45, interview*

The cisnormative assumption made by the gynaecologist highlights that he had not considered trans men’s health care, or previously provided health care to a trans man. Ethan believes that knowing that trans men exist and may not have a penis is basic knowledge regarding trans+ health and thus felt vulnerable as a health professional with little to no knowledge of trans+ people was performing an invasive procedure on him. This also highlights the vast differences in knowledge between health professionals working in the North, as some health professionals have knowledge of specific trans+ health needs, such as that described in Andrews experience, whereas others are not aware that trans+ people may need to access screening.

Additionally, health professionals contributed to discomfort through making inappropriate comments during the procedure. For example, Toothless, who is asexual and shared this with the health professional due to concern about how this may impact their experience of cervical screening:

“I told the nurse that because I thought that might make me feel more comfortable when they did it, and she said to me, oh but I want you to lose your virginity to someone special [laughs]. Um, that really was like a bit strange so I just went back to reception like booked a different nurse”

*Toothless, (he/they), trans man, 25-30, interview*

This comment made Toothless so uncomfortable that they requested a change of nurse to be able to undertake the appointment, which highlights the significance of being comfortable with the health professional and the impact that discomfort can have on screening. Further, Toothless’s experience of sharing that they are asexual is in stark contrast with Andrew’s experience, as presented previously in this chapter. Andrews’ health professional responded in an appropriate manner, reassured them about undergoing cervical screening, and created an overall comforting environment in which Andrew had a positive experience of screening, despite still experiencing pain. This contrasts with Toothless’s experience as the health professional was inappropriate and contributed to emotional discomfort.

Further, multiple participants disclosed that they have low expectations of health professionals’ knowledge of trans+ people, and that these expectations are rarely exceeded. For example, Dave who has been attending cervical screenings for 15 years shared that their GP is aware that they are non-binary, however it is “inevitable” that they will be misgendered during the procedure.

“But in the GP, yeah, or other cervical screening venues it's just it's always been pretty, yeah, like my expectations have been low and they've not been exceeded in in terms of like a nice trans experience, you know.”

“Wen I've gone for mine most recently has been at my GP in [city] erm, where they do know that, yeah, I I'm non-binary and you know, but they're just like a bit useless about it [laughs] so, I kind of just grin and bear the inevitable like gendered language and misgendering”

*Dave, (they/them), non-binary/agender, 30-35, interview*

The above excerpt highlights that throughout Dave’s cervical screening appointments, their expectations of being treated well as a trans+ person have continued to be low despite the significant time that the GP has been aware of their gender. Dave described their GPs as being “useless” about trans+ inclusion. Dave does not believe that their GPs are transphobic, but that they are lacking in necessary education to care for trans+ patients appropriately.

Participants were also not optimistic about HCP education in trans+ health being improved in the near future. For example, Robin shared that despite their GP surgery receiving training about trans+ health care, they are unsure if this garnered improved knowledge among the staff or whether the negative experiences with them will continue.

“I think there is definitely… a big gap in terms of educating GPs erm, and GP surgeries about trans health care. Erm, you know, I know plenty of people who've had to explain just what being trans means to nurses and doctors who just don't have a clue. Erm, I know my surgery have had some kind of training around it but I don't know how much of that has actually sunk in.”

*Robin, (they/them), transmasc non-binary, 35-40, interview*

Robin highlights that multiple trans+ people have had to explain what being transgender means to health professionals, which is basic information that should be taught at any training about trans+ people, and thus suggests that current medical education or training on trans inclusion is lacking. This also highlights the role of trans+ people in educating health professionals whilst waiting for training to be available and included as part of regulated programmes, as health professionals may only be aware of trans+ health through discussions with trans patients.

This was further expressed by Toothless who shared that the health professionals they have encountered often had limited knowledge of trans+ people in general, as well as providing appropriate cervical screening and other trans health care.

“But yeah, nurses aren’t, not around here anyway, they’re not very well trained in transgender people, not, not just cervical screening but anything”

“Um, my GP does know and she was really supportive at first like when I was changing my name by deed poll, but ever since I've started testosterone, she's been really not very helpful um like withholding my testosterone or sending me to a different clinic or not testing my blood for testosterone, I had to actually, my gender clinic made me travel all the way into [city] to get my blood done because they don't trust my GP.”

*Toothless, (he/they), trans man, 25-30, interview*

Toothless disclosed that their health professional was initially supportive of their trans+ identity, but began making accessing healthcare difficult once he began to medically transition. This lack of knowledge about, or intentional unwillingness to, care for Toothless once they began to use gender affirming hormones became so severe that the gender clinic required him to attend a different health service in order to get appropriate care. This experience affects Toothless’s trust in receiving appropriate care from their GP, thus impacting his experience of cervical screening as they feel a lack of support from health professionals, which can be exacerbated during an invasive procedure such as cervical screening.

Furthermore, participants disclosed that some health professionals made heteronormative assumptions. For example, some health professionals phrased questions in heteronormative ways which meant in order to answer, participants had to out themselves. This means that trans+ patients have to deal with both heteronormativity and cisnormativity within health services. Multiple participants disclosed that questions about sexual activity did not consider queer sex, as the questions were phrased around engaging in penetrative sex with a cis man, rather than considering other types of sex.

“When they ask the question first of all, which is like, you know, have you had sex it's like well, what do you define as that?”

*Leo, (they/them), non-binary, 30-35, interview*

This created discomfort as participants were unable of how to answer questions like this, as the answer health providers are often looking for relate to whether there could be a possibility of being pregnant, or whether they engage in penetrative sex which can be related to finding screening less uncomfortable. The phrasing of the question suggests to participants that health providers are expecting their patients to be heterosexual, which others LGBTQ+ people as they have to “out” themselves in order to answer questions in a useful way.

Further, Dave shared that multiple health professionals had been “bamboozled” as to how they could be sexually active without a possibility of being pregnant.

“I don't know like it's, it's still, it boggles my mind that like, and, you know, I've been getting smear tests or sexual health tests for like, you know, a long time, 15 years or whatever, people are still, just like, bamboozled by, like, could you be pregnant? Why wouldn't why, how could you possibly not be pregnant if you’re having sex? you know, like just these very sort of like really basic questions that seem to be, just like all these concepts seem to be stuck in people’s heads”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave disclosed their frustration at health providers continuing to be confused that they are engaging in sexual activity without the possibility of becoming pregnant. To Dave, this is frustrating as they have attended sexual health tests or cervical screening for 15 years and have provided information about queer sex to health professionals, however it seemed that despite repeated explanations over a 15-year period, change was slow to take place regarding the use of inclusive language. Heteronormative assumptions such as those shared by Leo and Dave lead to participants inferring that a lack of “basic” understanding of issues relating to queer sexualities would mean that health professionals’ awareness of trans+ issues is even less advanced. Thus, when faced with a lack of basic LGBTQ+ knowledge, trans+ people worry there will be minimal knowledge of trans+ people and their bodies.

Furthermore, Dave shared that in their experience, health providers tend to make heteronormative assumptions unless they are also queer, and thus have knowledge about LGBTQ+ people from lived experience rather than from medical education.

“I think unless the healthcare professionals also like, queer in some way I feel like there's just so much assumptions projected onto you that, and that seems to be kind of standard”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave disclosed that cisheteronormative assumptions are often inevitable unless the health provider is LGBTQ+ themselves. This highlights that there are gaps in the knowledge of some health providers that must be improved to help trans, and wider LGBTQ+ people, to feel more comfortable with health professionals, which in turn may improve their experiences of cervical screening.

Additionally, participants shared that health professionals often had limited knowledge of non-binary people. For example, Leo stated that their perception of health providers knowledge of trans+ people is limited to binary trans people, which refers to trans men and trans women.

“But it is like the whole thing where you have to vouch for yourself constantly, and that's again, like the double bind of like being non-binary as well, it's like I have to vouch for that as an existence.”

“I feel like if a trans man went for a screening and they were like on hormones, you know, it'd be an entirely different thing and the way they're being read would be an entirely different thing but for a non-binary person who, it's a kind of a historical term now, but who’s AFAB, you're gonna get viewed as that. Or at least I was.”

*Leo, (they/them), non-binary, 30-35, interview*

“I was out to my friends/family/wife but not to my GP (I still am not, this is entirely due to not wanting to have to explain and justify being non-binary)”

*Kit, (they/them), non-binary, 25-30, focus group*

Leo and Kit shared that health professionals were often unaware of what “non-binary” means and asked for an explanation, which felt like having to “vouch for” or “justify” non-binary as a valid gender. For Kit, this meant they did not disclose their identity to their GP due to the difficulty they would have with explaining and justifying their gender. Leo also disclosed that they felt taken less seriously as a non-binary person than they would if they were a trans man, and was viewed as a woman rather than a non-binary person. Further, Leo shared that they felt that trans+ people would be taken more seriously, such as their gender identity being seen as more valid or true, if they were medically transitioning, despite being aware that a medical transition does not make you more or less trans. For Leo, this was frustrating and led to gender dysphoria due to being perceived as the wrong gender. This created further discomfort during the screening procedure and meant that Leo did not feel as supported as they would have if the health professional had affirmed their gender, or at least accepted it as a valid gender.

Furthermore, multiple participants also disclosed that their experiences of trans-inclusive health professionals vary greatly depending on the area in which their appointment took place. For example, G shared that the health professionals they engaged with in a large city were significantly more knowledgeable about queer/trans issues than those in their small hometown.

“When I lived in [city] I’d been to the GU clinic a few times and every time I just told them, in a way I was confident and I was like you know if they don’t understand it I’m doing a service by explaining something, not that they were like 100% perfect but you know there’s like, when you’re in a city there’s lots of different communities of queer people around that do regularly visit the GU clinic so its just a completely different set of circumstances compared to here, I’ve kind of had to go back in the closet a little bit”

“I’m like, you know, realistic of the area that I live in and the type of people that I meet and have realistic expectations of what they like already know, or you know, not assuming that people are straight or not assuming that people are cis, they’re going to and you know, I’m not gonna change that”

*G, (they/them), non-binary, 25-30, interview*

Whilst living in a city, G felt more comfortable with sharing their trans+ identity and providing education to health professionals, which they felt was “doing a service” as they could improve the health professionals’ knowledge of trans+ health care, and thus improve the care they will provide to other trans+ patients. This again highlights the onus placed on trans+ people to educate health professionals whilst there is minimal mandated training on trans+ health. However, in their small hometown, G feels too uncomfortable and unsafe to share that they are trans+ and feels like they have “had to go back in the closet a little bit”. For example, in their hometown G assumes that they will be the first trans+ person their health providers have met and worries that providers will assume all their patients are cis and straight, which in their experience was not the case in the large city. The stark contrast between feeling confident to provide information about trans+ health to health professionals and not feeling able to share their identity highlights the difference in experiences trans+ people have dependent on the part of the country in which they live. Further, the data suggests that health professionals working in large cities may be more equipped to care for trans+ people and their bodies than those working in rural communities.

Health professionals’ attitudes and behaviours also affected patient experience of cervical screening. Multiple participants disclosed that their feelings of safety and support depended on whether the health professional behaved in a reassuring and trans inclusive way. For example, Bruce reported that multiple factors were necessary for their experience to be positive. This included feeling mentally able to attend screening, their gender feeling irrelevant, and having a “considerate and experienced” GP undertake the procedure.

“A lot of factors had to “align” for this experience to have played out the way it did. I was in the right place mentally, the GP was considerate and experienced, and my gender identity for the sake of the procedure going well was (arguably) irrelevant. If I had experienced any untoward reaction because of my identity, I’m not sure I would have been able to relax, so the attitude of the GP was paramount in maintaining my calm.”

*Bruce, (they/them), trans non-binary, 35-40, focus group*

For Bruce, the GP’s attitude and experience towards them as a trans+ person accessing cervical screening helped them to feel calm and relaxed. Bruce found their health provider reassuring and considerate, as well as being experienced in providing trans+ health, which eased discomfort about being cared for by someone who was unaware of this. For Bruce, being both experienced and knowledgeable, as well as being reassuring and considerate were “paramount” in helping them to feel calm, which suggests that both knowledge of trans+ issues and behaving in a reassuring way are necessary for producing a positive experience of cervical screening.

This is echoed by Jocelyn who shared that whether they have a positive or negative experience depends on the practitioner undertaking the procedure.

“Erm, it very much depends on the, the practitioner doing it. I think it's, you know, I've had, I know I had like one where it was just like over like that and it was like, oh okay, that’s fine, and you don't really think about anything then. Erm, as I say through that first one, that, I felt a lot of, arrgggh, horror, kinda trauma, but since then not a lot so I suppose that's a good thing.”

*Jocelyn, (any/they/she/he), androgynous, 40-45, interview, interview*

Jocelyn, who has attended screening multiple times, disclosed that he attended one screening appointment in which the procedure felt comfortable and easy, which she believes was due to the competency and comfort of the health provider. However, Jocelyn also disclosed that they had a negative experience, using the words “horror” and “trauma”. This was Jocelyns first screening appointment and they did not know what to expect, and the health professional started the procedure without explaining what was going to happen to his body. Jocelyn also found the procedure to be painful as a “scratchy stick”, which has now been changed to a small brush, was used to swab the cervix. Jocelyns first experience put her off attending cervical screening for a number of years, which highlights the importance of health providers behaviour in ensuring that patients continue to reattend cervical screening.

However, some participants disclosed behaviours experienced from health providers during cervical screening which impacted their feelings of safety, support and trust in the wider health system. For example, Ethan disclosed multiple experiences of health professionals not being trauma informed.

“[The doctor] said “but what's that got to do with you being an adult, that all happened in the past when you was a kid… he said “I wasn't even born when you were a kid so it doesn't matter” so clearly, he wasn't trauma informed”

“Yeah, they sort of decided I was misbehaving as a disabled person rather than somebody who was actually being quite triggered.”

*Ethan (he/him), trans man, 40-45, interview*

In both situations, Ethan had disclosed his experiences of childhood sexual abuse and that his trauma makes cervical screening difficult and triggering. One doctor questioned why this continued to affect Ethan, even though it happened before the doctor was born. This shows that the doctor was completely uninformed on trauma, which multiple participants disclosed that they felt was necessary to provide cervical screening. Additionally, a second doctor did not reassure or comfort Ethan during a screening appointment as they believed he was “misbehaving as a disabled person” rather than acknowledging that he was feeling uncomfortable and triggered. This made Ethan feel like the health professional was unable to see him as an individual past his disability, which suggests a need to improve HCPs knowledge about caring for disabled people. It also highlights the need to improve education about trauma and its impact on accessing health care such as cervical screening.

Furthermore, some participants disclosed experiencing judgement or inappropriate comments about their bodies, which caused them to feel uncomfortable and unsupported by the health professionals.

“She asked me to undress my lower half in privacy and left me behind a curtain without saying much else. When she returned and I was undressed, she stopped to look at me with what I vividly remember to be disgust, leading me to look away in embarrassment.”

“The doctor used several types of speculums and said she was struggling to access my cervix, saying “It’s clear you haven’t had kids”. She also asked me if I had ever had sex before, which didn’t feel great.”

*Blue, (they/them), non-binary, 30-35, focus group*

Blue shared that the health provider looked at them with what they perceived to be “disgust” and this in turn made them feel embarrassed and uncomfortable. Blue interpreted the HCP’s behaviour as an example of fatphobia, as they were judged and looked at negatively based on their weight. Further, the same health professional made inappropriate comments about Blue’s genitals due to them struggling with pain, as the health professional stated that it may be due to not having had kids, or not engaging in penetrative sex. This screening appointment was abandoned, and Blue later found out that the reason listed in their medical records was their “high BMI”, which left Blue feeling judged again, uncomfortable and frustrated that their weight had been used as a reason for something which it was not related to. Blue may have been able to undergo the procedure if the health professional had acted more kindly, considerate, or helped to reduce their discomfort.

Similarly, some participants shared that the procedure felt rushed, which made them feel uncared for, and like their needs as an individual were not considered:

“It's like if they've got a waiting room of 20/30 people and they just want to get them all done, then they just, I'm just another box.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan requires his health provider to be considerate of his needs as a disabled trans man with sexual trauma. For example, Ethan discloses their sexual trauma before each appointment to be treated in a trauma informed way. However, Ethan shared that sometimes he feels rushed and uncared for due to the health providers having to provide care to multiple patients, which leaves him feeling like “just another box”. This greatly impacts Ethans experience as he needs highly individualised care in order to combat the many difficulties he experiences during cervical screening.

Further, some participants disclosed that their difficulties were not taken seriously by health professionals. For example, Robin shared that their health provider rushed their appointment and was rude when Robin was finding the procedure painful:

“The nurse that did my last one down there was very impatient and, you know, a bit rude especially about you know when I complained about the speculum hurting and everything.”

“And like, if you tell them, it's it hurts, actually taking it seriously, that would be very helpful”

*Robin, (they/them), transmasc non-binary, 35-40, interview*

Robin shared that they felt unsupported by the health professional who did not offer a break, a smaller speculum, or any comfort when they found the procedure painful. They shared that their experience would have been better if the provider would’ve taken their pain seriously, and both knew how, and acted on, ways to reduce their pain.

Furthermore, Ryan shared that they received minimal support from the health provider during a painful procedure, and following this the health professional made an insensitive comment.

“Again, I was in a lot of pain and there was like, a lot of bleeding and like as they walked you out they you know as you go to get changed, or like, put your clothes back on, or whatever she's like, oh, she said “take some pads with you, you're quite traumatised down there” and it's like it's the worst thing you want to hear isn’t it about your genitalia is like, a nurse going oh, you're quite traumatized and I’m like, yeah, thanks.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

This comment left Ryan feeling shame for finding the procedure so painful, and frustration that the health professional was unaware or unwilling to provide comfort. Both Ryan and Robins testimony highlights the need for health professionals to be more aware of how to combat experiences of physical pain, and how to be sensitive and understanding to help patients to feel supported and cared for.

Additionally, many participants also shared that they felt more comfortable when health professionals explained the procedure and asked before continuing each step. This helped them to feel more in control of what was happening to their body, and to combat anxiety which arises from the uncertainty of the procedure. However, some participants shared that even when the procedure is explained, or when they attend their second screening appointment, they remain anxious about how the procedure will “play out”. For example, when asked about how they felt before their second screening exam, L responded:

“Nervous. Definitely, I wasn't sure, I knew what to expect, but obviously, you're never sure how it's going to play out.”

*L, (they/them), agender and outside of the gender binary, 25-30, interview*

L expressed a preference for the procedure being explained to them, however this did not combat all their anxiety about uncertainty related to the procedure. For example, L worried about attending screening with a different health professional as they were unaware of how they would act, and how this would impact the physical pain or emotions L experienced. Therefore, despite many participants sharing that being knowledgeable of the procedure helped to ease their anxiety, it is important to note that there may still be concerns about how each individual screening procedure will go.

Further, some participants shared that they had too many worries and concerns that even when health professionals were able to reassure them, there were other issues that this was not possible for. For example;

“[I felt] quite nervous and like when I would sit and speak to them and like you know I would be quite honest, that I’m nervous and maybe like well you know we can use like this speculum that’s smaller and blah blah and it’s like erm, even that didn’t really help because the nervousness then went to like, oh, you know, this is making me feel bad in terms of like how they’re handling like, erm, like sexuality or like gender”

*Leo, (they/them), non-binary, 30-35, interview*

Leo shared that they felt nervous and would disclose this to health professionals, who would do their best to reduce any anxiety, for example by offering to use a smaller speculum. However, there were anxieties that the health professional was unable to help with, such as anxiety about how the HCP will handle their gender and/or sexuality. This highlights the multitude of concerns that trans+ patients experience during cervical screening as even when multiple worries are tackled, there are other issues that create anxiety relating to the procedure.

Participants also revealed that the health providers behaviours affected whether they felt comfortable enough to “come out”. Multiple participants shared that they decided whether to come out to health professionals based on the “vibe” they got from them, which referred to whether they seemed open and understanding. This included multiple participants deciding not to disclose their gender to their health provider, and instead presenting as a cis woman to avoid discomfort, such as inappropriate questioning or being treated badly due to their trans+ status. For G, as discussed in theme two subtheme seven, this was also related to living in a rural area in which they believed that the health professionals would have limited understanding of trans+ inclusion and therefore opted to hide their identity to prevent uncomfortable conversations.

Finally, Ethan, who felt increased pain during cervical screening due to testosterone use, was aware that topical oestrogen may reduce the pain he experiences during screening, however, Ethan was unable to access this.

“E: Mhm. I have done, the GP won't prescribe it unless the unless the gender clinic decide that they will authorise it. But getting the GP and the gender clinic to talk to each other is another story.

G: Yeah, there’s lots of things you've got to jump through to get anything done.

E: Yeah. Yeah. It's a bit like trying to start PREP the, the GP saying it's a trans issue, the gender clinic are saying no, it's a GP issue.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan disclosed his attempts to be prescribed topical oestrogen from both his GP and gender clinic, however both said this was under the remit of the other service. Therefore, Ethan has been unable to access a prescription which may reduce his pain, and thus improve his experience of cervical screening. Ethan shared that this was frustrating and impacted his health experience, as well as trust in being provided appropriate health care due to being passed between two services.

This subtheme therefore highlights the vast differences in health professionals’ knowledge, experience, attitudes and behaviours whilst caring for trans+ people. Each of these elements impact trans+ peoples experiences of cervical screening, as the health professionals had a large influence over whether the screening appointment felt positive or negative.

## Theme three – Relief or regret: participants thoughts and experiences following screening appointments

This theme explores participants thoughts and feelings following screening appointments. This includes feeling relief that the procedure was over for another year, to distress that it had to be undertaken at all. Further, it explores participants feelings following unsuccessful screening appointments, which refer to those where a sample was not taken. Finally, I discuss how participants feel about reattending cervical screening following appointments.

### 5.3.1 – Emotions experienced by participants following successful and unsuccessful screening appointments

Participants experienced various emotions following their screening appointments. For example, a number of participants expressed that they felt relief that it was over, such as Jocelyn who believes that attending screening is a “good thing” and is glad to have done it once the appointment is over, despite finding it uncomfortable. In contrast, other participants do not feel relieved to have attended screening and instead experience heightened dysphoria and discomfort following their appointment.

“The dysphoria does tend to kick in, kind of like, afterwards rather than, well it’s kind of during as well but I'm like I said I'm sedated at that point so it's a bit less of a thing erm, so it tends to like kick in afterwards, I'm just like, oh god, you know, and I'm like in the recovery bit and I just have to sit there in pain because it takes a while and all this kind of stuff and like, that's when that kind of hits.”

“So yeah, it's just like, going through all this, what will be physical pain and the psychological pain of the actual event. But then all the stuff around it and it's like going through it for what feels like nothing… nothing good is going to happen because even if it comes, even when it comes back and says like oh there's nothing wrong with it, it's like, well, I still have to go through that experience, you know?”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

As above, Ryan feels extremely uncomfortable following the appointment whilst waiting to be discharged and throughout the rest of the day. Their dysphoria is not as severe during the appointment as they are sedated and their thoughts are clouded, however once the sedation has worn off, they experience physical and psychological pain that they do not deem worth the benefit of being aware of potential health issues. Therefore, in contrast to Jocelyn, Ryan does not feel relieved that their appointment is over or that it was a good thing to attend, and instead feel physical and emotional pain that they do not feel is worth the benefits of screening.

Additionally, three participants experienced “unsuccessful screening” meaning the practitioner was not able to find the cervix or collect a sample. This occurred once for Blue, and multiple times for G and Leo. All three participants left feeling disappointed and as though they had “failed” as they had been through an uncomfortable experience but no sample was taken, and thus the appointment had no benefit. G and Leo also discussed blaming themselves for not being able to provide a sample:

“I really like beat myself up about it as well, because it's like, it’s my fault, it's like my shortcomings… like going home and just lying there like, you know, like even the clothes I was wearing, I was like, did I wear the right clothes like, you know, should I have not worn my dungarees \*laughs\*… like and it's just like yeah just like just not good feelings just like feeling really uncomfortable and disappointed and upset.”

*Leo, (they/them), non-binary, 30-35, interview*

“[The nurse is] like oh you know sometimes if people are like more sexually active then they can find it easier and I’m like, oh sorry that I’m not, and I know she didn’t mean it like that but I felt a little bit like oh right okay, it’s kind of linked to something that I feel negative about, like oh no one wants me and that that’s why I’m now in pain, it’s kind of a bit of a jump but it’s true it made me think that like if I could just keep a partner and I just had like normal sex then I wouldn’t be in pain right now”

“And with the reasons this wasn’t easy for me, this is everything to do with me, what I’m doing, the shape of my body, what I’m not doing, and my discomfort with gynae things, it’s just all things that are in my head or in my body so I felt like, you know, why can’t you just be normal and this would be easier and again just these feelings of like, it’s because I’m unconventional, that’s why this didn’t work”

*G, (they/them), non-binary, 25-30, interview*

Both G and Leo left the appointments feeling disappointed and blaming themselves, which resulted in them overanalysing themselves and potential reasons for the screening being unsuccessful. Leo shared that they “beat themselves up about it”, and believed it was their own “fault” and “shortcomings”, even considering whether their wearing of dungarees could’ve been a reason the screening was unsuccessful. Leo had a very strong reaction to their screening being unsuccessful, which included even having thoughts that their clothing may have affected the ability to undergo the screening. This shows the distress Leo experienced following abandoning the procedure, as they became determined to find the reason, and blamed themself for this. Further, G’s nurse mentioned that not engaging in penetrative sex may make screening more painful which they took to mean that if they had “normal” sex they would be in less pain. G had shared earlier that the typical definition of sex shared by HCPs was not inclusive or correct, however the headspace they are in following screening made them think if they were more “normal” they would not be in pain. Additionally, G shared that the reasons they found screening difficult – such as having an anteverted cervix, discomfort with gynaecological examinations, dysphoria, physical pain and not engaging in penetrative sex – were all things to do with themself as a person and thus used these reasons to blame themself for finding screening difficult. Thus, G positioned themself as “not normal” and viewed this as the reason they were unable to undergo screening. This therefore shows that unsuccessful screenings can have a negative impact on TMNB patients, including their thoughts about themselves and their bodies.

Interestingly, some participants demonstrated determination and reclaiming agency, despite cervical screening usually placing patients in a vulnerable and powerless situation. For example, after the initial disappointment of unsuccessful screenings, Leo became determined to undergo successful screening. They attended three or four times before successfully providing a sample, and described appointments being stopped due to being too nervous or in pain, however they had the resolve to continue to attend:

“Like with the determination that it could be done differently, Like, you know…I was like, it's offputting to go through all that kind of stuff, but then, at the same time, it's like erm… I was like, I'm the kind of person were in, like, if I've got kind of a barrier, I'm like, I want to get over that so I was like, well, how can I do like that then? I was like, I would go home and I would look stuff up again and be like, are there any resources for like LGBT people I don't know about and then like just keeping an eye out on that kind of stuff”

*Leo, (they/them), non-binary, 30-35, interview*

As we can see, Leo experienced many uncomfortable and unsuccessful screening attempts but was determined to return. They searched for information on ways to reduce their anxiety and physical pain and used these, which along with diagnosis of and treatment for a chronic illness, they were able to have a successful screening appointment. They have written down their needs during the appointment, such as avoiding certain areas that may cause pain due to their chronic illness and that they found a longer, thinner speculum to be less painful rather than the smallest speculum which did not work, to share with health professionals at future appointments to ensure that future screenings are also successful. This shows that despite a long and negative process to achieving successful screening, they are willing and determined to attend future appointments and are able to advocate for their own needs for the screening to be as comfortable as possible in order to allow the collection of a sample.

Some participants developed coping methods for dealing with the discomfort of CCS after the appointment. For example, Robin shared that they experienced heightened dysphoria following their CCS appointment due to the misgendering and reminder of the incongruence between their body and their gender, and thus wear a binder at home, which helps to reduce dysphoria although they would not usually wear this when alone, because of their dysphoria being more severe.

“It's just that, you know, it's just a reminder, isn't it? And especially being misgendered throughout just isn't very comfortable. And so, like afterwards, well, you know, I don't tend to like wear a binder when I'm at home and stuff like that, usually only when I'm going out, but like after an appointments, I probably would, you know, because it just reminds me of everything that's uncomfortable.”

*Robin, (they/them), transmasc non-binary, 35-40, interview*

Furthermore, Dave shared that discussing their experience with their partners, friends or trans+ people who can empathise with them helps to alleviate the discomfort following cervical screening. This helps Dave to decompress and move on with their day.

“I would want to like, have a bit of a rant to one of my partners or pals or fellow like trans people, like you know, that, that was a unpleasant experience and we can kind of decompress together with some shared erm, well, being able to empathise with that experience with each other. And, you know, hours later I'm just getting on with my day and it's fine”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Therefore, this subtheme explores different ways that CCS can impact TMNB after the appointment is over. Some participants shared that they felt relieved and glad to have attended, whereas others experience heightened dysphoria, discomfort and/or blamed themselves for struggling during the appointment. This highlights the importance of improving screening experiences in order to improve how TMNB feel following their appointment, as well as to improve experiences and uptake of CCS.

### 5.3.2 – The impact of screening experiences on future reattendance.

Some participants reported positive screening experiences, which left them hopeful for similarly positive future appointments. In contrast, some participants had negative experiences that meant they skipped or delayed screening appointments, dreaded future screening, or wished to never return. This subtheme explores the impact of screening experiences on whether patients will attend future screening appointments.

Andrew had a positive experience of cervical screening and thus shared that they do not feel as worried about going to future screenings due to knowing what is involved, feeling respected by the health professional, and knowing that it is important for his body.

“I feel extremely positive about going to future screenings, even with the discomfort involved, as I know how important they are to attend from a medical viewpoint.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Clearly, it seems that having a positive experience of cervical screening can ease decisions about reattending and improve patient likelihood of reattending screening in the future. This highlights the importance of ameliorating screening experiences to improve uptake of CCS.

The idea of continuing to attend screening despite discomfort was also echoed by Leo, who had multiple very difficult experiences but continues to attend screening due to the health benefits. This links to the use of a cost/benefit analysis to decide whether or not to attend screening, as explored in theme one. For Leo, the health benefits outweigh the discomfort, despite having multiple negative experiences at previous appointments.

“So I'm waiting for that but kind of like dreading it and hoping it's kind of never happens.”

“And so yeah, so it's all that kind of feeling of like, oh god, I've got to do this again. I'm gonna have to explain somebody again. Like, I don't want to because it feels very, because it's very personal, you know, yeah no, if I was gonna repeat myself I’d just say like yeah erm, it’s not put me off completely even though I’ve had some really horrible, horrible experiences, and I’d always encourage people to get them.”

*Leo, (they/them), non-binary, 30-35, interview*

Leo continued to worry about and even dread going to future screening, but they will attend future screening appointments to ensure they are aware of any potential health issues. Leo discusses that they feel discomfort in having to explain their health needs and previous issues with cervical screening to a HCP who they may never have met before, which they would need to do in order to ensure a successful screening appointment. They share that they dread doing this, and attending their next appointment, but that they will continue to attend and to encourage others to despite incredibly negative experiences.

The findings also highlight that the behaviour of health professionals can impact a patient’s likelihood of returning to screening. This is evident as a number of participants shared that they would request the same health professional if they attended in the future due to receiving appropriate care from them and wanting this to continue in future appointments. Further, being familiar with the health professional reduces uncertainty about the screening procedure, and concerns about the health professionals attitudes towards them as a trans+ person or as someone who finds screening difficult.

“I would probably still attend future screenings and would request the same nurse again if possible. Unless there was a trans specific clinic, I could access I wouldn’t feel great about having to go again and would put it off as much as I could.”

*Kit (they/them), non-binary, 25-30, focus group*

However, this also highlights the anticipation of negative behaviours from other health professionals as participants would like to be secure in knowing their HCP will be knowledgeable and trans-friendly but worry that another HCP would not do the same. Therefore, several participants expressed desire to attend trans-specific clinics so they could be sure that they would be treated appropriately. This suggests that despite the ability of some HCPs to provide appropriate care for TMNB during cervical screening, this is not universal, and thus more training is required to ensure all TMNB can access cervical screening with HCPs they feel comfortable with. Additionally, the above quote shows that despite having a good experience with the previous nurse, other issues can make screening difficult to reattend in the future and thus more changes are needed to address other areas which make screening challenging for TMNB.

Furthermore, L disclosed that they had positive experiences with their health professionals which helped them to feel relaxed, however they now worry that this may change if they moved practice.

“So, it worries me a little bit to be like, if I change practice, it's not going to be like that. But I think that you know, after our conversation and after those two experiences, I would be more comfortable speaking up. If I felt that, you know, it wasn't going as it should”.

*L, (they/them), agender and outside of the gender binary, 25-30, interview*

L shared that after being cared for by two knowledgeable and reassuring health professionals, they may not be afforded the same treatment if they were to move practice and worry how this would impact their screening experience. However, L feels confident in speaking up and ensuring that they are treated appropriately if this became the case.

Contrastingly, negative experiences can cause TMNB to delay, avoid or refuse to attend screening in the future. For example, several participants shared that they skipped screening appointments due to negative or traumatic past experiences of screening.

“The very first time I went for one, it was it was quite traumatic, it wasn't, it wasn't done nicely so that, that put me off for a while.”

*Jocelyn, (any/they/she/he), androgynous, 40-45, interview, interview*

“To be perfectly honest, so after that, last appointment where the nurse was rude and didn't use lube and was just a really unpleasant experience, I did skip one. And so yeah, there was like, a 6 year a gap between, between two of the screenings just based on that.”

*Robin, (they/them), transmasc non-binary, 35-40, interview*

Jocelyn and Robin were both put off by unpleasant experiences of CCS in which they did not feel properly taken care of by health professionals, which led to them delaying their reattendance of screening. Robin shared that the nurse did not use lube and behaved in a rude manner, which put them off reattending screening due to worries of similar experiences being repeated. Additionally, Jocelyn shared that their first experience of screening was “traumatic” and “wasn’t done nicely”, which suggests the health professional did not behave appropriately, and thus was put off attending future screenings for a number of years. This shows the importance of having positive or neutral experiences of CCS to not deter patients from reattending screening.

Additionally, two participants reported worrying about CCS regularly, despite not being due for their next appointment. Blue shared that they feel conflicted about reattending as they find the screening procedure to be uncomfortable but are aware of the importance in continuing to attend to be aware of potential health issues. This leaves them worrying about screening, including worries about whether to reattend and about the procedure itself regularly.

“I feel conflicted about attending again and it’s something I regularly worry about, even though I don’t have to attend for a while.”

*Blue, (they/them), non-binary, 30-35, focus group*

Further, Ethan shared that he constantly worries about and dreads CCS. Despite his invitation letter not being due for 8 months, Ethan feels a “sense of doom” when he hears the post as he worries that the post will contain the invitation. The words “doom” and “dread” highlight the distress Ethan experiences both at CCS, and when thinking about CCS, which impacts his day-to-day life.

“Even though I'm, I'm not due for annual recall [for 8 months], I still wake up every day dreading it.”

“I get a sense of doom whenever I hear the post. Is today going to be the letter?”

*Ethan (he/him), trans man, 40-45, interview*

Ethan experiencing feelings of dread and doom about cervical screening every day is an extreme reaction to screening, which may be due to hyperfocus as a result of Ethan’s disabilities. However, multiple other participants also discussed feeling worried at points when they are not due for the procedure. Further, it highlights that improvements to the screening procedure are necessary to improve both uptake of CCS, and also the mental health of patients who spend considerable time worrying about CCS.

Finally, two participants reported that avoiding cervical screening was an important factor in deciding whether to access gender affirming surgery. For example, Toothless shared a desire to never attend screening again due to the extreme dysphoria and discomfort they experienced during the procedure. This shows that negative experiences of screening can be so severe that this becomes a factor in determining whether patients would like to have a hysterectomy to remove the discomfort and dysphoria of attending CCS.

“Um, kind of like, kind of like I never want to do it again. Yeah, it wasn't like, it's definitely made me think more like yeah, I probably want to have a hysterectomy at some point. Because it's just a dysphoric experience, like, I just wouldn't feel comfortable in the same way, like, I wouldn't feel comfortable getting pregnant or other things, yeah.”

*Toothless, (he/they), trans man, 25-30, interview*

Therefore, previous experiences of screening influence the likelihood of reattendance, and the level of worry patients have before their appointments. Patients who have positive experiences, characterised by limited gender dysphoria and HCPs who were able to provide sensitive and appropriate care, were more likely to feel okay about reattending screening in the future. However, negative experiences, such as heightened gender dysphoria, discomfort, or a negative experience with the HCP, can impact whether a patient will reattend and may cause more worry before their next appointment. Therefore, taking steps to provide a better experience of CCS can influence whether patients attend screening in the future.

## Theme four - Making screening more manageable: recommendations for improving cervical screening for trans+ people

Theme four encapsulates participants’ recommendations for improving cervical screening experiences for trans and non-binary people. This includes improving health professionals’ behaviours, attitudes and education; modifications to the procedure; de-gendering the perception of cervical screening through de-gendering messaging and communication; and miscellaneous advice which trans+ participants had for other trans+ people.

Before exploring this theme, it is important to consider the complexity of improving cervical cancer screening experiences. Multiple improvements must be implemented to ameliorate trans+ peoples experiences of cervical screening. Some trans+ people experience multiple intersecting factors which produce a negative experience of cervical screening. The removal of some barriers to screening may improve trans+ experiences of screening but there may continue to be discomfort and distress due to other factors, which often cannot be removed. For example:

“Because it's loads of things mixed together, right, it's the pain, it's the, it's the, it's, so there's that side of it, there's the and then there's the dysphoria on top of it and then there's all this other stuff so it's like actually if we could take a couple of things away, like they can't take the dysphoria angle of it off like ever because at the end of the day it's poking about in gendered bits so there's always going to be that dysphoria attached to it, which is which there is, attached to a lot of things, you know, it's not just the smear test, so yeah, I mean like if I could take as many of those barriers as possible, but I know a lot of them are like the pain is like I said, it's partly because I’m autistic, and it's partly because my physiologic-, my things are in the wrong, in weird places. Like I've got one. I don't use it. It's not even configured properly. And you know, so I think, yeah, stuff like that would be much, I don’t know, yeah, just a bit more kind of honesty in the, just being able to have like more open conversations with kind of healthcare people, like not having to feel like I have to explain things to everybody all the time”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

As above, Ryan expressed that removing barriers would positively impact their experience of cervical screening, and thus effort should be taken to improve various aspects of cervical screening. However, it feels impossible to them that all barriers would be removed, and therefore they would still have to tackle discomfort, such as the guilt and shame they feel about their partner having to accompany them to cervical screening. As a result, Ryan feels that no matter what changes happen, there will always be something that causes them distress in relation to attending screening. However, removing as many of these as possible would lessen the distress they feel when attending screening.

Therefore, multiple changes are required to improve trans+ peoples experiences of cervical screening. This includes improvements in medical education, making modifications to the procedure, and de-gendering the procedure. However, there are also a number of ways trans+ people can help themselves when accessing and attending screening whilst waiting for health service based changes to be developed and implemented, and for the results of these to be seen by trans+ patients. Thus, when reading this chapter, the reader must consider that although there may be an impact from each individual change, the improvement of as many aspects as possible is vital to reduce the distress often experienced by trans+ people when attending screening.

### 5.4.1 The importance of choice; potential modifications to the procedure

A key thread that was identified throughout the participants’ accounts was the importance of having more choice in how the procedure is undertaken. This involves being given options regarding the procedure, such as those explored within this subtheme, and deciding which they would find more comfortable. The importance of choice is present throughout this chapter as an important method of ensuring that trans+ patients are able to access a screening exam which accommodates their individual needs. Participants shared that this would help them to feel more in control of the procedure, and that they would be able to inform practitioners about what would make them feel more or less comfortable. Modifications in this context refers to changing certain aspects of the procedure to make it more accessible and potentially easier for patients. The following modifications explored within this subtheme include allowing patients to make more choices, using a smaller speculum, self-insertion of the speculum, and bringing a trusted person to the appointment.

#### Choice, agency and autonomy

Improving autonomy and choice in cervical screening is especially important for Leo, as after multiple unsuccessful screening appointments, Leo wrote themselves a set of instructions for a successful screening to occur, as discussed in theme three subtheme one, Leo is able to advocate for themselves and their needs which helps them to undergo successful screening procedures as they are able to make choices which makes them feel more comfortable and able to continue with the procedure. Thus, allowing for more choices may help to improve trans+ peoples experiences and ability to access cervical screening:

“I think probably a theme in what I'm gonna say to you is like, yeah, that should always be an option, would you like a reminder of the process or are you comfortable with how things, or this is what's changed, because like it has changed over the years like where I've had them so and yeah, erm you know, maybe a little bit of why, like oh best practice is to do, x, y and z, I'd like that.”

“It'd be nice to feel like I think ultimately, the best case scenario would to in that, you know, 10/15 minute appointment to feel like you've been seen as an individual, not just like a walking cervix to be scrubbed or whatever, erm swabbed, you know, like you've been seen as individual and your individual needs have been like considered and, you know, I think that would make it feel like a respectful process and then you can leave having had a slightly less awful time”

*Dave, (they/them), non-binary/agender, 30-35, interview*

As above, Dave’s response to many of the suggested modifications were that even if they themselves would not find that particular suggestion helpful, they believe it should still be offered as someone else may find it useful. For example, Dave suggested that options should be shared at the start of the appointment which can be decided by the patient, such as asking whether or not they would like an explanation of the procedure. Dave also stated that this would help participants to feel more respected as their individual needs would be considered, and that this would improve the overall experience.

Further, Jocelyn suggested that people may make different choices at different stages of their life. For example, Jocelyn shared that for their first screening appointment they would have preferred to have the procedure explained and taken slowly, however now he would prefer the screening to be done as quickly as possible and without the explanation.

“Georgia: Do you think like having just all these questions at the start, like being asked, you know, do you want me to explain it or just get on with it, like do you think that would –

Jocelyn: That would be good for me, I mean, personally, I'd be like, yeah, because I, you know, you know basically what's gonna happen, so… certainly thinking back to my first time had things gone maybe at a slower pace and had all these different bits gone through better certainly, for the first time, screening I think it would be really, really good for first time people going in to have it done, particularly if they are and trans or non-binary and they are concerned about how their body's gonna be treated and whether their body is going to be treated in a respectful way and that stage it's a good thing… I think obviously explaining to start with what's going to happen is good but I’m one of these people that just say just do it, again, it's, it's a good thing that they're offering, the, you know, going step by step, it could be beneficial but for me I’d just be like meh, just get on with it”

*Jocelyn, (any/they/she/he), androgynous, 40-45, interview*

The additional agency provided by allowing patients to make choices about their own bodies in a situation in which they are usually powerless may help them to feel more comfortable and in control of the procedure. Further, offering questions at the start of the appointment may give power back to patients who may be unaware that they are able to make choices about what happens to them and their bodies during screening. Jocelyn, and other participants, agreed that having a health practitioner offer various choices at the beginning of the appointment would be useful as not all potential modifications will be helpful to each patient and thus patients should be given choices in what will help them personally, as explored below. This highlights the need to offer different options to different people in order to ensure everyone is able to engage in cervical screening in the way they are most comfortable.

Another method suggested by participants to increase a sense of empowerment and therefore ease the procedure was having a conversation about individual needs before the procedure begins. This was viewed as being useful to ensure that trans+ patients are being treated with respect by allowing patients to choose what words should be used to describe them, as well as to combat assumptions.

“I just think more questions or more erm, you know, just taking two minutes to kind of ask me hey, you know, what should we call you, how do you get like to go by and which of this information, which of this relevant information about like, you know, sexual health or whatever is personal to you and then they can sort of answer their questions around that, and seek, seek kind of nuance around what they've got from you instead of just barrelling in with these assumptions.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

As discussed earlier, Dave had multiple experiences of assumptions being made about their sexuality and gender which they found frustrating, and which created concerns about how they will be treated during various appointments. As a result, Dave suggested that health professionals asking more questions may help to reduce assumptions made. For example, Dave is often frustrated that health professionals assume there is a possibility that they could be pregnant due to them being sexually active, and thus asking about their sexual partners could reduce these assumptions being made. Having more open and inclusive questions rather than making assumptions would indicate to trans+, and LGBTQ+, patients that the health professional has considered their needs, and thus may reduce anxiety about how they would be treated if they shared their gender or sexuality. Further, it would give trans+ patients the time to share their pronouns or any preferred terms they would like to be used about their body, thus allowing them to feel cared for more holistically.

#### Using a smaller speculum

As indicated throughout this findings chapter, many issues shared by participants about the cervical screening procedure result from the use of the speculum, such as physical pain or reminders of sexual trauma, therefore it is important to minimise the negative experiences associated with the speculum. One way to ease the use of the speculum is offering a smaller speculum during the cervical screening procedure as this may reduce pain among some patients. Multiple participants had been offered, and used, a smaller speculum, which reduced pain among most of those who opted for this. However, other participants had never been offered the use of a smaller speculum and were unaware that this was an option. For example, Andrew shared that their health professional was aware of the potential for screening to be more painful due to their testosterone use:

“Using smaller speculums with more lubricant really really helps, due to the fact testosterone causes a lack of elasticity and dryness…We already used the smallest sized speculum available for my smear specifically because I’m a trans man, which definitely made the whole experience more comfortable”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Lubrication and a small speculum had a big influence on Andrew’s comfort, especially as someone who uses testosterone. She shared that this reduced pain and made the whole experience more comfortable. As discussed earlier, Andrew also found it comforting that the health professional was able to offer this approach, which also contributed to his having a relatively positive experience. Andrew shared that the modifications themselves, as well as the practitioner suggesting modifications and thus showing that they have considered the needs of trans+ patients, can be helpful in improving experiences of cervical screening. Therefore, having a conversation with the health professional about potential ways to reduce discomfort and allowing patients to choose can help them to feel empowered and cared for.

A smaller speculum can also be specifically helpful for people with a history sexual trauma who may struggle with penetration.

“It’s good to err on the side of not hurting people, it's probably good practice, and you know, like, and you don't know what kind of past experiences people have had, or trauma they might have around these things. So I think more choice and more autonomy, giving people it as an option is definitely better.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

“They do use erm, I'm quite, I'm a medium to sort of large person in build and sometimes they get a medium, medium speculum out but when I do mention the childhood thing they do change it to a smaller one. So, that's I’d say,…that's pretty good.”

*Ethan (he/him), trans man, 40-45, interview*

Dave suggested that using a smaller speculum should be offered more due to the potential for causing less pain. Further, Ethan disclosed that in his experience, health practitioners often switch to a smaller speculum when he mentions that he is a survivor of childhood sexual abuse. Despite Ethan continuing to feel pain, the smaller speculum causes less pain than another sized speculum and thus they prefer the former.

Not all participants benefitted from a smaller speculum. Leo, in contrast, was offered a smaller speculum however did not find that this eased their pain.

“Yeah, for me, actually for me, I found out during this successful one because she was much more like you know, in a way accountable for like what she was doing and being like open about the process that what worked for me was not the smallest one but like the longest and thinnest one.”

*Leo, (they/them), non-binary, 30-35, interview*

As above, Leo’s discomfort was reduced by using the longest, thinnest speculum. This shows that different size and shape speculums will reduce discomfort differently, and thus the use of various speculums may allow one which causes less pain to be identified. Leo also found it useful to be told that the longer, thinner speculum was the speculum through which they had their first and only successful screening examination and that they will now request this specific speculum type at future appointments. This highlights the importance of an open conversation between patients and practitioners, as this discussion may lead to improvements in Leo’s screening experiences in the future.

However, multiple participants had never been offered to use a smaller speculum despite finding the procedure to be painful.

“Yeah, I mean, if that was an option, they've never really mentioned that they could do that, they just go here’s the thing… No, I've never really, I mean, maybe it’s a thing that's come out since I have my last one but, maybe it's because I'm sedated, they're just like oh they’ll be fine either way, or maybe I've already had the smallest one and that still hurts, but I don't know, it's definitely not a discussion I think I've had”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Despite finding cervical screening so painful that they require to be sedated for the procedure, Ryan had never been offered a smaller speculum. However, Ryan did acknowledge that they may have used a smaller speculum without this being disclosed. It is clear from Ryan’s response that they would have appreciated being given this as an option. Furthermore, as discussed above, it may be the shape rather than the size that is important so discussing the speculum prior to the procedure is important as patients can share their previous experience with different speculums and request the one which works well for them and their bodies. However, if patients are not aware that there are options regarding the size/shape of the speculum they would not be able to request one to reduce the pain, thus removing their autonomy within the procedure.

Therefore, health professionals should be aware that they should offer patients a smaller speculum and be consistent in doing this. Further, increasing the awareness of smaller speculums as an option is important so that trans+ patients can request this themselves in cases where health professionals omit this as an option. It would also be useful for patients to be involved in a discussion about which speculum they found easier, more comfortable and less painful so that they are able to request this type of speculum in the future.

#### Self-insertion of the speculum

Another modification which one participant was offered, was for the patient to insert the speculum themselves. The HCP would then swab the cervix and/or do necessary adjustments. Participants had varying opinions on whether they would find this useful, however, as consistent with other ideas, they agreed that this should be something offered in case it is comforting to other people. For example, G shared that self-insertion is something they would feel more comfortable with and would want to try.

“Georgia: some things like inserting the speculum yourself and then the practitioner doing the actual thing, how do you think you would feel about that

G: I’d definitely be better with that, definitely I would try that for sure… Yeah definitely because like if you, you can dictate when you’re like moving that in terms of like the pain and everything then like once you’re sufficiently in there it would hurt a lot less like once you’re already in if they had to move it and things I’m sure would be less painful than the actual insertion”

*G, (they/them), non-binary, 25-30, interview*

G shared that the ability to “dictate” where the speculum moves would be helpful as they would be able to stop immediately if a certain movement was painful and try another way, thus giving them more control and autonomy in the procedure. Further, Andrew also felt that they may find self-insertion reassuring, however they have concerns about whether they would be able to do this correctly.

“The idea of inserting the speculum myself is interesting. Not something I would have considered beforehand, but likely would have been more reassuring! Though at the same time, I wouldn’t really know how to do it, so would also likely cause me stress on that front.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Andrews interest in self-insertion, but doubt in their ability to successfully do this, suggests that Andrew could find self-insertion helpful if they were talked through how to insert the speculum, and became more confident in doing this for future screenings.

However, some participants also shared that having the health professional, who is trained and experienced in using a speculum, provided comfort as they could be certain that the procedure was happening correctly. Multiple participants also shared that the concern about not inserting the speculum correctly means they would not attempt to insert the speculum themselves. For example, Jocelyn immediately shut down self-insertion as an option as they would not find it useful, and instead would feel worried that they would do it wrong:

“I don’t think I'd like that, I don’t think I’d know how to do that, and I don’t think I’d feel like I’d got it right.”

*Jocelyn, (any/they/she/he), androgynous, 40-45, interview, interview*

One participant disclosed that their health professional suggested that this was an option, however they did not feel like it was one they were able to take at that time:

“Yeah, I mean that actually was offered to me. I think it wasn’t offered to me like a thing that was gonna happen, it was just like, oh yeah, you could have that, you know, but I feel like with me, I would rather somebody else do it because I feel like I wouldn't get it right, you know, I don't know what they're looking for and yeah, I know that that's obviously I'm not looking at it myself, but like, um, yeah, I just feel like they need to do it but at the same time yeah it would be more, like I did have the urge when I was like lying there last time to be like I need to like guide it myself because if she's rooting around, you know, I probably know the best way of like dealing with that. But then she got there in the end so I'm like it's fine. So my answer to that is basically, maybe it would be useful, I don't know, it might be useful.”

*Leo, (they/them), non-binary, 30-35, interview*

As above, Leo had conflicting opinions about self-insertion and were unsure of whether it would be helpful to them. However, Leo was the only person who had had this offered to them, which further highlights the differences in knowledge that health professionals have about reducing pain or discomfort, as some health professionals offered self-insertion as an option whereas others did not even offer a smaller speculum.

Furthermore, some participants shared that they experience difficulties with the insertion of anything, so inserting the speculum themselves would not be helpful for reasons such as gender dysphoria or physical difficulties:

“Um, while I can see why that might be helpful for some people, I think for me there would not be much difference. Like, I mean, I struggle even inserting tampons, so like you just consciously relax and to get the angle right, because I actually have a tilted cervix so I have to lie pretty specifically and which involves the use of both of my hands when I'm sort of tilting myself for the speculum and for the swabbing, so for me, that would make it less easy actually.”

*L, (they/them), agender and outside of the gender binary, 25-30, interview*

“Um, I know that some people who have like frozen their eggs and then need like internal examinations, have preferred that, ‘cos they've got like the control over I think I'd still find that, just the insertion of anything dysphoric, yeah”

*Toothless, (he/they), trans man, 25-30, interview*

As above, for Toothless the act of inserting anything into the vagina induced dysphoria, and thus self-insertion of the speculum would not improve their own experience. However, they also shared that they know other people who have frozen their eggs and opted to self-insert during internal examinations due to the increased control and agency over their bodies. Therefore, participants discussed varying opinions on whether self-insertion would be useful for them, however all participants stated or alluded to believing this should be offered as an option as it may be useful to other patients.

#### Taking a trusted person

The final modification was the participant taking a trusted person into the appointment. Consistently with other modifications, participants had different opinions on whether they would find this comforting but believed it should be offered as an option for those who may find it useful:

“I personally, wouldn't feel that was necessary and because it's just like compartmentalised in my brain as just like a thing for my body as a machine to go and do and like get checked, and again, it should always be an option to take a mate or chaperone in, for sure. And like you know to respect for the staff to respect, like, your, the person who comes with you as well and whatever their relationship is to you to kind of respect, that is important.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

As above, Dave would not find it useful to take a trusted person with them, however they believe patients should be given this option. Further, Dave emphasised the importance of ensuring that the person who accompanies the patient is also treated with respect, such as ensuring the right pronouns are used and respecting the relationship between the patient and their chosen person, such as respecting queer relationships. This was further echoed by Jamie who shared that:

“They also mentioned I could bring a friend, but to be honest I have no one I’d feel comfortable coming other than my husband, and I feel that would either be not allowed or frowned upon somehow.”

*Jamie (they/them), transmascs non-binary, 25-30, focus group*

Jamie disclosed that they would feel more comfortable if someone else was in the room with them, however they were concerned about judgement from health professionals if they brought their husband. This may be for a variety of reasons, such as a lack of trust in the health professional being respective of LGBTQ+ relationships. This highlights the importance of health professionals ensuring that patients are aware that their chosen person can be anyone they feel comfortable with, and that both people will be treated with respect during the appointment.

Three participants had taken a trusted person into their screening appointments. Some participants said that they had been offered a chaperone, which they declined, however they may have taken someone with them if they knew it could be a trusted person who they chose, and thus would feel comfortable that the additional person in the room would be affirming and able to advocate for them. For example, Blue found comfort in having their partner attend the appointment and hold their hand during the procedure. Also, G took a friend for their first screening appointment and found this to be comforting and helpful in staying calm:

“And also it was a really good distraction....so that’s why the first time I like took a friend in with me and I think mainly the reason that was helpful was I that I felt like the nurse would believe me that I’ve had these previous experiences”

“I had that comfort of my friend being there and sort of my outside identity away from that away from that clinical room was still kind of connected to me”

“So I think I went away from that with like, good distractions in place and my friend talking to me, and I was allowed, you know I think she’d booked a double appointment for me and told me to like go and wait in the waiting room and only leave when I felt ready and I think I had that backing with my friend being there with me that it didn’t seem like a weird thing to do so I was actually comfortable… although I found it like really really useful I did also feel a bit babyish, I felt like, and I think that’s why the second time I was like ah I’m an adult now so I should be able to do this and then I couldn’t do it”

*G, (they/them), non-binary, 25-30, interview*

As above, G found that having their friend accompany them to the appointment provided comfort in various ways. For example, they did not feel comfortable with coming out to the HCP but found having a friend there who used their correct pronouns and affirmed their gender to be helpful in relieving dysphoria. However, G also said they felt “babyish” for needing someone with them. This led to G attending their second appointment alone, which G then found much more difficult, and the HCP was not able to collect a sample. This therefore highlights the impact that taking a friend had on G as they felt much more comfortable, calm and supported during the procedure, and shared that they believe that not taking someone with them to the second appointment may have contributed to their unsuccessful appointment.

Additionally, due to Ethan’s disabilities, somebody must accompany him to his screening appointments. Ethan feels much more comfortable when this person, either his mum or a carer, go into the exam room with him.

“It helps to know that erm, I'm not going to be sort of taken to a strange room afterwards and sort of sat on my own in some waiting room. But from a trans point of view, even the disability one, it doesn't really. I think, from a PTSD point of view, it helps but it doesn't help with with the dysphoria. By the time I'm actually in the room and sort of getting ready to take my clothes off as it were, the dysphoria is already there. I could have 20 people in that room and it wouldn't make a difference.”

“Yes, I've had, I've had mum coming with me and I've had a career take me, accompany once and she's refused to come in and that's made me feel sense of abandonment…I think it's the sense of abandonment to do with childhood and stuff.””

“Because it's familiarity. I know they're not gonna go anywhere. They're the ones that are going to be taking me out of that room.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan shared that having someone enter the exam room with him is helpful with his PTSD, however they would not find this helpful specifically with issues that may arise due to being a trans man. For example, Ethan finds it comforting to have a familiar person who can push his wheelchair rather than being pushed into a “strange room” by a health professional. Ethan disclosed that once his carer refused to accompany him into the exam room which made him feel abandoned, which was reminiscent of his experiences of childhood sexual abuse. Ethan found this particular screening appointment to be very triggering and distressing due to being alone with a stranger during a vulnerable and invasive procedure. Therefore, it can be comforting to have a trusted friend attend the appointment, especially for those who have experienced sexual trauma.

In contrast, other participants stated that having a trusted person in the room with them would create further discomfort during the appointment:

“Toothless: So normally I have people come in with me to appointments, but that one was just like I'm gonna go by myself. Yeah.

Georgia: Mhm, why did you decide to go to that one by yourself?

Toothless: Um, because you're kind of half naked, particularly when you're not wearing a dress or anything and also like because I'm not, this is in hindsight, I was in lot of pain during the procedure and I think having someone hear me in pain would have been just as embarrassing, I was happy that it was just me”

*Toothless, (he/they), trans man, 25-30, interview*

As above, Toothless decided against taking someone into the appointment with him due to embarrassment and shame about being undressed and having someone witness them in pain. This was further echoed by L who said someone seeing their pain would be “humiliating”. Therefore, despite Toothless usually taking a trusted person to medical appointments with them, he did not feel comfortable with this for cervical screening due to the nature of the procedure. Therefore, there is a difference of opinion on whether taking a trusted friend into the screening appointment would reduce or create discomfort, however the participants recognise that this is something that could help other patients, and thus should be routinely offered.

### 5.4.2 – Improving medical education and training

#### Improving the awareness of trans+ health through the education of healthcare professionals

Following the evidence from previous themes, it seems that health professionals require further education on a variety of areas, from understanding transgender identities and combatting assumptions, to trans-specific health needs, including cervical screening. Additionally, participants shared that they have more positive experiences of cervical screening, and general health care, when their HCP is sensitive, understanding, and knowledgeable of trans+ health needs. Furthermore, participants who have had positive previous experiences with health professionals shared that they were able to be more trusting, relaxed and less worried about how other HCPs will treat them during CCS. This shows that education must be improved across health services to improve cervical screening for trans+ people.

Experiences disclosed by participants also highlighted that many trans+ people have had to educate HCPs on trans+ health. Further, multiple participants stated that in their experience, unless the HCP is queer themselves, they often know little to nothing about trans+ people or trans+ health. For example, a number of trans+ participants disclosed that they or their friends have had to explain what being trans or non-binary meant. Participants shared that although they were often happy to educate practitioners for practitioners to be more understanding of their next trans+ patients, they were frustrated that the responsibility to educate health professionals about trans+ health was put on trans+ people, rather than on medical schools or other training.

“Georgia: so with you saying, like helping other trans and non-binary people in the future, if you explain, if you like talk about being trans to a health professional and then the next person they have, they'll kind of know a bit more. Is that what you mean?

Leo: Yeah, yeah, that's how it feels to me. I'm like it probably wouldn't impact them that much but maybe it would, you know”

*Leo, (they/them), non-binary, 30-35, interview*

Leo and G shared that explaining various trans+ issues to health professionals feels ‘worth’ it as this knowledge can be taken and used when treating other trans+ patients. Whilst some trans+ people are comfortable with providing this education during appointments, improved medical education is required to remove the onus from trans+ patients and to ensure each trans+ person is able to be cared for by trans+ informed professionals rather than providing education.

Further, some participants had provided feedback to health professionals, for example to their GP or a sexual health clinic, about caring for trans+ patients and had positive opinions of clinics in which they had seen this feedback come into fruition.

“[A sexual health clinic in a large city], I I think they're much better, I think they're much more kind of like open-minded and actually have responded to some feedback, you know, they're like tell us how your appointment was and stuff, and I've noticed that since sort of giving them some feedback about assuming people who you have sex with and what your pronouns might be etc, they've been like quite proactive in not having any assumptions and, and sort of at least seeming to have an open mind. Erm… So I think they're really good.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave shared positive opinions of a sexual health clinic which had changed their practice following some of Dave’s feedback to be more inclusive of trans+ people. This process works to reassure Dave that when they reattend appointments at this clinic, they have less worries about being treated negatively due to their trans status and their frustrations at various assumptions are reduced. Therefore, responding to feedback or education from trans+ people and making meaningful changes can impact trans patients’ experiences of health services.

Additionally, Leo, Ryan and Kit stated that the responses of their health professionals to their finding screening difficult made them feel like the health professional was expecting them to find it easy, and were unaware of reasons that people may find screening to be difficult, or ways to support patients who find screening difficult. Therefore, when asked more specifically about what they would like health professionals to be taught about trans+ cervical screening, Kit responded:

“More awareness of why it might be more difficult, better understanding of queer health generally by clinicians…More training and awareness on why it might be difficult for trans/queer people too.”

*Kit (they/them), non-binary, 25-30, focus group*

As above, Kit would feel more comfortable if the health professionals were more aware of reasons that people may find screening difficult, as well as being more understanding and knowledgeable about queer health in general. This idea is consistent among all participants, who all disclosed their desire for health practitioners to receive more education about LGBTQ+, and specifically trans+, health.

Finally, this subtheme indicates that it is vital to ensure that improving health workers knowledge of and behaviours towards trans+ people extends to all health care staff and not just those attending medical schools:

“The healthcare provider experience as a whole like it has to be holistic, like there's no point getting like a nice smear test that gives you a warm fuzzy, gender affirming feeling if you are, you know, getting like misgendered at the, by the receptionist and, and your other healthcare is being done in like and not very kind of like understanding way I suppose”

*Dave, (they/them), non-binary/agender, 30-35, interview*

Dave emphasises the need for all staff working in health care settings to be educated on trans+ issues. For example, they highlight that patient experience can be negatively affected by other staff such as receptionists who may misgender or deadname them. Therefore, the impact that non-medical staff may have on trans+ peoples experiences of health services must be considered when taking steps to improve trans+ issues in health services.

#### Ensuring all health practitioners are taught the principles of trauma informed care

All participants reported that the way health professionals behaved affected their experience of CCS. Multiple participants stated that from their perspective, health professionals were not trauma informed, and that they believe this should be a requirement for all practitioners who perform cervical screening. Trauma informed care within cervical screening should provide information about different types of trauma and how this may impact health experiences, as well as ways to alleviate the stress caused by attending CCS. Aspects of trauma informed care may also be useful to patients who had not experienced trauma, or who felt unable to disclose this and therefore should be implemented for all patients. This subtheme therefore explores recommendations for changes that HCPs can make to the way they care for trans+ patients to improve their experiences of CCS, and thus uptake of CCS.

Participants shared that feeling in control of the procedure helped them to have a more positive experience. One way in which participants were able to feel more in control was having the procedure explained to them and being asked permission to continue before next steps.

“They would, explaining what they were doing as they were doing it so there was never any like sudden touching or unexpected like movement”.

*L, (they/them), agender/outside of the gender binary, 25-30*

L shared that having the procedure explained and being asked for consent before continuing meant they felt more comfortable as there was no sudden touching or unexpected movement. This allowed L to feel in control during the procedure and cared for by HCPs. This is an important part of trauma informed care, which some participants shared they believe should be required for all health professionals who perform CCS procedures.

“I think anybody doing that kind of work should be trauma informed but they’re clearly not”.

“It would be good if everybody that was doing screening could have special, some sort of specialist training about CSA [childhood sexual abuse] and about issues that trans patients might face. Especially sort of aftercare afterwards. Would you like to sit somewhere quietly? Would you like to have a drink? Are you feeling okay? But no, there’s not, there's never been any of that anywhere”.

*Ethan (he/him), trans man, 40-45, interview*

Ethan suggested that trauma informed care should involve aftercare, such as checking in with patients who have disclosed trauma or providing a place to sit quietly and destress. Ethan felt distress at undergoing a difficult procedure and then having to leave the appointment and carry on with his day as if nothing had happened, and instead would have preferred a space to decompress from the experience before leaving the hospital. Additionally, providers should have an open conversation about things that may potentially be triggering for their patients, if the patient wishes. For example, Ethan shared that being asked to use the word “stop” was triggering due to previous experiences of sexual assault when they had used the word stop and been ignored.

“If I was to be able to say a certain word to the practitioner doing it and everything just stops, that, that would be, that would work a lot better than the sort of responsibility being put on me to physically say the word stop.”

*Ethan (he/him), trans man, 40-45, interview*

Ethan also shared that creating a “safety word” which when said, the procedure is stopped immediately. He shared that a chosen word would be more appropriate and would help them to feel more comfortable in trusting that the procedure would end if they requested this.

Furthermore, Kit shared that being asked about a history of assault helped them to feel comfortable sharing this and started a conversation about things that may be helpful to them. Following a negative experience in which Kit cried and endured the pain and emotional discomfort and was not offered to pause the appointment, Kit had a better experience due to the health professional taking steps to ensure they felt safe and cared for.

“[The second time] was done by a nurse at my GP practice and this was a better experience. She fully explained the procedure and showed me the equipment, she asked about previous screenings and about any history of assault. I explained the first screening as above. She used a smaller speculum and made sure I knew we could pause or completely stop at any point. It was still painful but I felt more in control of what was happening”

*Kit, (they/them), non-binary, 25-30, focus group*

Kit was able to express their difficulty of accessing screening due to sexual assault, which resulted in a smaller speculum being used and being given the option to pause or stop at any point. This helped them to feel safe and in control of the procedure, which reduced their emotional/psychological distress from their trauma. This therefore shows the importance of providing participants with more control in order to reduce their distress and improve their overall experience of CCS.

#### Showing consideration, reassurance and understanding towards trans+ patients

Participants shared that they felt more comfortable when health professionals behaved in a considerate, reassuring and understanding way. This involves considering individual needs and being aware of potential difficulties which trans+ patients may face when attending screening.

As discussed throughout the findings chapter, Andrew disclosed that they believe their positive experiences of screening were due to the reassuring and understanding nature of their health professional. Andrew stated that if not for the health professional being knowledgeable of trans+ issues, being comforting, and checking in with Andrew before continuing, her experience would not have been as positive.

“My nurse for the first appointment explained everything very clearly and asked repeatedly if I was ok and if it was alright to continue... it very much made the whole experience far more reassuring considering I had absolutely no idea what to expect from the situation”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Therefore, it is vital to ensure that health professionals conducting cervical screenings provide support and reassurance to trans+ patients, such as explaining the procedure, checking in with their emotions, and asking for consent before continuing. Additionally, Andrew’s health professional was able to share information about trans health (such as the use of testosterone potentially making screening more difficult, or the potential for labs to refuse to test the sample due to the male name) which made Andrew feel comfortable knowing that he was in capable and considerate hands. Further, this reduces worries about negative reactions to trans+ identities as patients can be more assured that the health provider is supportive of trans+ people. Therefore, having knowledge of, and sharing trans-specific information about cervical screening can help patients to feel safe and comfortable during screening.

Further, L disclosed the importance of the health professional creating an environment in which they felt comfortable to share any worries or discomfort they were experiencing. This helped them to feel more in control of the procedure, which is an important aspect for feeling comfortable in screening as discussed in the previous subtheme, as well as feeling supported by the health professional.

“I felt they made the environment, like, feel like I could voice any discomfort that I may be having”

*L, (they/them), agender and outside of the gender binary, 25-30, interview*

In contrast, Ryan’s health professionals did not respond positively when they were having difficulties with screening. Ryan found this lack of understanding frustrating when attending cervical screening in hospitals as they assumed that everyone who requires a hospital appointment to attend screening must find screening difficult in some way. However, Ryan perceives that health professionals have lacked empathy regarding their difficulties.

“You know, like especially if you're going to hospital, if you've gone to hospitals, have it done, it's usually, because I would assume that there's a reason, you can't have it done your GP, you know? And so it's like so I assume everyone who goes for one at the hospital, or most people go to the hospital have got something going on, right? So it's just like, I would just like a bit more sympathy so that this is not pleasant you know....It's weird, isn't it? Like, just something like, so tiny just like digs up like a whole like just kind of stuff like going around your head.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

Ryan would therefore find it valuable to experience more sympathy and understanding from health professionals when they are finding screening to be difficult.

Expressing understanding about potential difficulties can be shown in multiple ways. For example, by asking participants about their previous experiences of screening and offering comfort or coping methods for screening. Multiple participants referenced feeling comfortable and cared for when the HCP asked if they have been screened before, what this experience was like, and if there was anything that helped as this showed that the health professional was considering their needs and would take the time to ensure that the procedure was as comfortable as possible. Most participants felt that the HCPs listened and responded to their concerns, however Blue shared that having a pillow underneath their hips meant the practitioner was “able to insert the speculum with some discomfort but no pain", but when requesting this on a subsequent appointment this was ignored.

Finally, multiple participants expressed that health professionals having indicators of being queer friendly helped them to feel more comfortable due to having a visual expression of being LGBTQ+ inclusive. For example, wearing a rainbow or pronoun pin can help a patient to know that if they came out to the health professional there would not be a negative reaction.

“Obviously there are things that, that people in health care can do to change the situation which probably would help, so for example things like the rainbow badge scheme … I would feel a lot more safe to erm come out if I saw those indicators erm so that could be one thing that would improve my experience”

*G, (they/them), non-binary, 25-30, interview*

“She had this rainbow pin on so I was like, I'm gonna risk it and be like this person seems kind and nice and, you know, like open”

*Leo, (they/them), non-binary, 30-35, interview*

G and Leo expressed that they felt more comfortable with sharing their trans identities when there was a visual cue from health professionals that they were LGBTQ+ friendly. For example, wearing a rainbow pin meant some participants felt able to disclose their identity and any worries they were having in relation to screening and their gender. However, since the COVID-19 pandemic, the rainbow symbol has been used to represent the NHS, which creates confusion around whether a badge being worn is to symbolise acceptance of the LGBTQ+ community or in support of the NHS:

“The rainbow is like these symbol of the NHS now, it's like and now it's difficult for like work out whether somebody is like just supportive of the NHS or supportive of like LGBT people”

*Leo, (they/them), non-binary, 30-35, interview*

Therefore, the use of the rainbow lanyard or pin may not be as impactful on trans+ people’s feelings of safety as before the COVID-19 pandemic.

### 5.4.3 De-gendering cervical screening is good for everyone

Many participants disclosed that de-gendering the cervical screening procedure and any communication surrounding this would help them to feel more comfortable with attending screening appointments. This requires a change in language used, such as using more neutral and non-gendered language when discussing cervical screening and during appointments, as well as updating the current health records system. Further, participants who attended cervical screening in hospitals expressed discomfort with pink, mum-focused posters and decor within gynaecology wards. Therefore, it may be beneficial to make these spaces more neutral.

Some participants disclosed that some terminology used by health professionals can worsen their gender dysphoria. Participants shared that more neutral language would help them to feel more comfortable. As a result, some participants expressed the importance of health professionals carefully selecting appropriate words to use when caring for trans+ patients. Participants gave suggestions of potential changes in terminology; however, they agreed that asking patients which words they would feel more comfortable with would be best practice.

“I guess, yeah, just like I'd love less gender language and erm, yeah, and less assumptions about type of sex, you have and with whom and what that means and then just being treated kind of neutrally and respectfully and that, that would be nice.”

*Dave, (they/them), non-binary/agender, 30-35, interview*

“It'll probably be things like, can you not use the word vagina or can you not use, erm, yeah, something like that, can you instead use the word vulva because I don't mind that word or go for really medical terms and just say cervix, any kind of word that I'm not attached to.”

*Jack, (they/he), transmasculine non-binary, 25-30, interview*

As above, Jack would feel more comfortable with words that they are able to view as more neutral and detached from their perception of gender. For example, Jack would find using the term “vulva” instead of “vagina” to be more comfortable. This is potentially due to the relatively recent introduction of the term “vulva” into mainstream society, which has meant that, unlike vagina, Jack has not experienced the repeated association of vulva with gender, but rather with a body part. This allows Jack to view “vulva” as a name for a body part, rather than a gendered term describing a part of the traditionally female body, and thus is less impactful with regards to gender dysphoria.

De-gendering cervical screening also requires combatting issues which arise due to the current health records system. This involves changing the automated recall system to ensure all people who are eligible for cervical screening are invited, rather than inviting all people registered as female within the health records and ignoring that transmasculine people registered as male may require screening. Updating this system is vital both for ensuring that all transmasculine people eligible for cervical screening are invited to attend, but also to reduce discomfort and/or distress experienced by women who do not require screening but receive an invitation. For example, Robin shared that they have transfeminine friends who receive cervical screening invitations and find this dysphoria inducing due to the reminder that they do not have a traditionally female body. Further, Ryan shared that they have cis women friends who become distressed when receiving a cervical screening invitation due to the reminder of previous fertility issues:

“Yeah, it's like I've had, I've had friends who've had miscarriages and they've kind of described the whole…you know, people said that have lost their child, which is an awful experience, they still get post through, they still get letters or invites or marketing stuff because no one's taking them off the right thing, whatever, and then that's very traumatizing for them, you know. So it's, it's yeah there's this kind of definitely stuff around yeah, it would help cis women a lot”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

As above, the current system which invites people based on the sex registered on their health records and their age both excludes people who are eligible for screening, and invites people who are not eligible for screening as it does not consider other circumstances, such as the existence of transfeminine people or cisgender women who have had total hysterectomies and therefore no longer require screening. This highlights the importance of updating the cervical screening invitation system to be more appropriate due to the benefits that this would have for trans+ people, including transmasculine and transfeminine people, as well as for cisgender women who no longer require cervical screening.

### 5.4.4 The importance of community in coping with cervical screening

Participants discussed the importance of discussing cervical screening with other transmasculine people due to their ability to understand the emotional difficulties of the situation, and ability to share advice or solidarity. This is especially important in cases where the health professionals were unable to provide support or offer small changes to improve the procedure for trans+ people. This subtheme discusses the importance of community, and advice shared by trans+ people for other trans+ people.

Multiple participants shared that discussing the screening procedure with other trans+ people helped them to destress or decompress from the emotional discomfort of the procedure due to the mutual understandings of finding cervical screening difficult.

“I spoke with my partner, who is also a trans man, about this as well – as we both ended up booking the screening appointments for around the same time. This was reassuring as we were able to compare experiences, and considering both were positive (if not awkward due to the whole nature of a cervical screen), it helped make future appointments less foreboding.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

As above, a number of trans+ participants felt that discussing screening specifically with other trans+ people helped them to feel more aligned with their gender, as they were aware that other trans+ people attend screening, and feel like their feelings and difficulties were understood.

Some participants shared that their experience of talking to cis women left them feeling frustrated and not cared about due to their friends inability to sympathise with the difficulties that trans+ people may experience during cervical screening.

“And especially talking to cis, women who haven't had a problem with it. Because there's cis women that are like what's wrong with you, like it's fine, like you know, I've never had any problems like nobody really likes it and just going like you don't really get, you don't really get it from quite the perspective that I'm coming from.”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

“I think with other trans people there's definitely like the potential, you know, for like dysphoria around body parts and uncomfortable, you know, conversations to be had with healthcare providers erm… and potential for misgendering etc which introduces a sort of different nuance erm to those conversations that we might have and, you know, with like people that, you know, my cis friends, I might share that as well, but with less of a kind of mutual, understanding base, you know,”

*Dave, (they/them), non-binary/agender, 30-35, interview*

This lack of understanding from cisgender women compared with the mutual understanding and empathy from other trans+ people highlights the importance of trans+ people having a community in order to cope with difficult situations. This is true both in providing emotional support, as well as offering advice on how to cope during the appointment.

#### Trans+ people know best: advice from trans+ people to other trans+ people.

Some participants disclosed that prior to screening, they asked queer/trans+ friends for advice on how to cope with cervical screening.

“I spoke to queer and trans friends to try figure out anything I could do to make it less dysphoric.”

“Wearing favourite/affirming clothes, speaking about it and negative feelings associated with it to friends, wearing favourite perfume/cologne, fidget and sensory toys. Tried all which helped a little”

*Kit (they/them), non-binary, 25-30, focus group*

Kit’s friends suggested that they should wear affirming clothes or perfume/cologne to align themselves with their gender and feel more comfortable in their bodies. Further, they shared the importance of talking about cervical screening with friends, including the negative aspects of screening in order to gain support. Finally, Kit’s friends suggested taking fidget or sensory toys because Kit is autistic and fidget/sensory toys may help them to regulate their emotions, or can provide a sensory distraction. Kit shared that they tried all of these suggestions, which helped a small amount but their screening procedure remained uncomfortable due to other barriers which were unable to be removed. However, this highlights the importance of discussing screening with trans+ friends as they were able to provide suggestions which reduced some of the discomfort Kit experienced during screening.

Further, Andrew shared that they were able to book their appointment during a monthly testosterone injection, and to book the screening appointment to be done in the same appointment as their testosterone injection. This took away anxiety related to being a masculine-presenting person asking receptionists to book a cervical screening appointment as they did not have to out themselves as trans+ or deal with any untoward reactions as he knew the health professional who booked the appointment was supportive of their gender.

“My second test, which was last month, was a far better experience. I’d booked a double appointment with the same nurse to do my testosterone injection first and then the cervical screen, which in some ways was kind of reassuring? It was like, I could have something gender re-affirming right before something that would make me uncomfortable, and it balanced it out a bit.”

“Having my testosterone injection at the same appointment as the cervical screen was also great, as a positive helped overshadow a more uncomfortable one.”

*Andrew, (any pronouns, primarily he/they/she), fluid transmasc, 25-30, focus group*

Further, having the testosterone injection in the same appointment meant that Andrew was able to feel affirmed in her gender due to taking steps to further their medical transition. Andrew disclosed that despite the cervical screening being uncomfortable, this was able to be balanced out by having the testosterone injection done at the same time, meaning the appointment wasn’t fully focused around cervical screening as a procedure for ‘women’, but as two procedures done to take care of their body.

Finally, Robin and Ryan shared that doing something affirming after the procedure helps them to feel more comfortable in their gender following a dysphoria-inducing procedure. For example, Robin shared that they wear their binder while at home, which they usually only do when leaving the house, in order to feel more comfortable in their body. Further, Ryan likes to make plans which reaffirm their gender, and make them feel like the day is less of a “waste” due to the time taken off work to do something uncomfortable.

“Like it's, setting up something gender affirming to do afterwards, it’ll be like okay, cool, I'm gonna go and, I don't know what, you know, I'm gonna I'll go home and… oh, look at some clothes or I'll read a, or you know, there's a, there's like a feminist queer bookshop in the city and get a book, but you know, like just something that recentres me in my identity as opposed to this kind of floating thing over here I've had, what I've panicked myself into thinking I've made it all up doing the course of the event, so you know, I probably do something like, like that, you know, so look at clothes or look at accessories or you know go oh actually you do need to book voice therapy or you know something like that, you know, so I've got something that, so if I've got to take the day off or I'm going to take majority of the day off, like I've not completely wasted it. I've done something to balance it off”

*Ryan, (they/them), “How do you describe your gender” “with difficulty”, non-binary demiguy, 35-40, interview*

As above, Ryan takes steps to recentre themselves in their body and gender, or to “balance” off the discomfort of the screening procedure. For example, Ryan visits a queer bookshop or books their gender affirming voice therapy after the procedure to realign themselves with their gender, by doing something to make them feel more comfortable or to further their transition, following the discomfort of screening. This highlights the impact that screening has on Ryan, as they have had to consider many ways to cope with cervical screening including planning the before, during and after in order to minimise their distress. Further, whilst Ryan uses many coping methods, screening continues to be really difficult and thus in addition to the potential changes trans+ people can do for themselves, changes must be made to cervical screening procedure, policy and medical education in order to improve cervical screening.

## Conclusion to the findings chapter

The analysis revealed themes based on the participants’ experiences and views that demonstrated both negative and positive sides of cervical screening. Negative experiences often resulted from a mixture of intense gender dysphoria, physical or emotional discomfort, and/or negative experiences with health professionals. In contrast, a small number of participants were able to have a positive/neutral experience. These participants disclosed that their comfort was in a large part due to the health professionals who behaved in a knowledgeable and reassuring way. Further, these participants reported feeling like they were in a “good headspace” or feeling affirmed in their body outside of cervical screening, which helped them to remember that attending cervical screening does not mean anything with regards to their gender. Further, the findings chapter outlines a number of potential ways that cervical screening can be improved, both from participants experiences or through suggestions they believe may be useful. The following chapter will discuss the findings in relation to current literature, and attend to the gaps identified in the literature review.

# Chapter six - Discussion

## Introduction

Through an in-depth qualitative exploration, this thesis has demonstrated the complexities of trans+ peoples’ experiences of cervical screening, including multiple barriers and facilitators to screening and the impact of these on patient experiences. In this chapter I situate the findings of this thesis within the current published research on trans+ experiences of cervical screening and wider trans health and cervical screening research. Next, two important contributions to knowledge made in relation to the research questions below are explored: the importance of intersectionality within trans+ health research, and the use of a novel approach to allow deeper insight into trans+ peoples experiences of cervical screening. This chapter also includes a discussion of a broad range of literature concerned with trans+ peoples experiences of accessing health services, including but not limited to cervical screening and other sexual and reproductive health services. I also draw upon wider literature about experiences of cervical screening to explore how trans+ peoples experiences of screening may be similar or different from other communities, and to share how this research study complements what is already known. Following this is a discussion of the quality of this thesis through outlining the strengths and limitations of research study using various markers of quality within qualitative research. Finally, I present an in-depth discussion of reflexivity within this thesis, including discussing my positionality and the thought processes behind each decision made throughout this study.

**Primary research question**

What are the experiences of transgender men and non-binary people when accessing and attending cervical cancer screening in Northern England?

**Secondary research questions**

What can we learn from participants experiences to better understand and support future cervical screening appointments?

What factors influence whether the screening procedure is positive, neutral, or negative?

What improvements, modifications or changes do TMNB think are most important to improve these experiences?

What are the implications of this for future policy development and changes to health care practice within the NHS?

## 6.1 Findings in relation to existing literature

In this section I explore the findings of this thesis theme by theme in relation to the wider published literature.

### 6.1.1 - Theme One: Factors affecting decisions to attend screening

One of the main findings of this thesis is the complexities of deciding whether to attend cervical screening. Various factors which influence participants decisions-making about whether to attend, or reattend, cervical screening were identified within theme one. These included health maintenance, feeling ignored by health systems, worries relating to the procedure such as experiencing heightened gender dysphoria or the impact of sexual trauma, and anxiety about how they will be treated by health professionals. Multiple participants shared that when deciding whether to attend cervical screening, they weighed the “risks and benefits” of attending or not attending screening. This involved considering whether the health benefit of knowing whether or not they were at risk of cervical cancer was worth undergoing cervical screening and the difficulties that this involved. Within this research, all but one participant had attended cervical screening, so this thesis is not able to discuss participants experiences of deciding against attending cervical screening.

The findings of this thesis highlight that although trans+ people understand the importance of cervical screening for health maintenance, additional factors can make the choice to attend difficult. For some participants, the need to be aware of their health meant they never considered not attending cervical screening but continued to have difficult experiences when attending. In contrast, other participants referenced their uncertainty of whether undergoing screening was worth the health benefit due to the severe negative experiences they had. For example, the findings highlight that the interaction of multiple factors, such as gender dysphoria, anticipating discrimination from health professionals, a history of sexual trauma or the impact of disability, can make participants question whether going to the appointment is worth the benefit of knowing they are not at risk of developing cervical cancer. Gender dysphoria is often cited as the main reason that trans+ people avoid cervical screening (Roznovjak *et al.*, 2023). However, complexities of this are often lost in previous research. For example, research cites gender dysphoria as a reason that someone may avoid cervical screening or may find it more difficult, but the interaction of this with other factors such as sexual trauma is often lost. Further, previous research has also found that gender dysphoria can be a motivating factor for cervical screening, as one participant in a US study stated that he attended screening due to fears of heightened gender dysphoria if he developed cervical cancer, and thus attended screening to reduce the likeliness of this (Peitzmeier *et al.*, 2017). Therefore, this thesis provides a more nuanced understanding of gender dysphoria by exploring how it may be affected by other factors during cervical screening, such as a history of sexual trauma or the health professionals’ attitudes and behaviours, which will be discussed further in theme two.

Additionally, systemic barriers to cervical screening were identified within this thesis, which participants reported made them feel ignored and invisible within health care systems, and thus less trusting of accessing services such as cervical screening. These included health professionals’ refusal to change participants names on NHS records and participants not being invited to cervical screening due to having a male gender marker, or that they had been warned that this may occur if they changed their gender marker. This means that trans+ people registered as male must request access to cervical screening themselves, as stated by Cancer Research UK (Berner, 2024) which is a significant barrier to screening (Vincent, 2018b; Connolly, Hughes and Berner, 2020). This highlights that health records are currently not sufficient in recognising trans+ people, including their chosen name and their gender identity. If health records do not include gender identity, chosen names and pronouns then these elements may not be available to healthcare teams, which increases the likeliness of unintentionally causing harm through misgendering or deadnaming patients (Boutilier *et al.*, 2024). Further, the current system which invites all people registered as female within the NHS means that some cisgender women who do not require screening, for example due to having a hysterectomy, as well as transfeminine people who register as female and do not have a cervix are also sent invitations despite this not being necessary (Dhillon *et al.*, 2020). Two participants in my study shared that they have cisgender and trans women friends who had received unnecessary screening invitations, which caused them distress. Similarly, transmasculine people registered as male are not invited to, and may struggle to access other traditionally gendered services such as breast cancer screening (Gomez *et al.*, 2021). This shows that the current invitation system both includes people who do not require screening and excludes others who do. The lack of consideration for including trans+ people within the health system, and the lack of education around trans+ health among health professionals led to some trans+ participants feeling that their existence was not considered by the health system or health professionals; recommendations for improving this are explored within Chapter 7: Implications. Participants reported that this lack of trans+ inclusion in health education, policy and practice led to them feeling ignored by health services or like they did not belong there. Participants reported that this made them feel less trust in being cared for appropriately, and thus they felt nervous when attending or avoided attending health services such as cervical screening. This sentiment was also found within other studies where both trans+ patients and providers of cervical screening reported that trans+ people are often invisible and ignored within research, policy and practice, including a qualitative grounded theory study based in the US (Bernstein *et al.*, 2017) and an Australian study exploring providers perceptions of cervical screening for trans+ people (Gibson *et al.*, 2021).

Finally, many participants reported that they had intentionally delayed attending cervical screening, which referred to waiting longer than recommended to attend screening, or skipping an invited screening (for example attending screening at six yearly intervals rather than three). For example, participants reported that they are currently delaying attending their first cervical screening appointment because they were concerned about coping with anticipated gender dysphoria and mistreatment from health professionals during an invasive procedure. Participants shared that they thought mistreatment from health professionals, such as being misgendered, was an inevitable part of attending cervical screening and thus had to consider whether this would have a considerable impact on their mental health, which for some participants resulted in delaying screening appointments until they felt more capable of contending with this. Similarly, in Aotearoa, New Zealand, 30% of trans+ participants who delayed screening reported that this was due to concern about how they would be treated by health professionals (Carroll *et al.*, 2023). Particular concerns reported in the Carroll *et al.*, (2023) study were the lack of consideration of trans+ people within the cervical screening programme in Aotearoa, the impact of negative previous medical encounters and the lack of trauma informed care among health professionals. Multiple participants within the Carroll *et al.*, (2023) study and this thesis reported delaying or skipping a screening appointment following a previous negative experience, for example following a negative experience with a healthcare professional or experiencing physical pain. The influence of previous negative experiences on future reattendance is discussed later in this chapter when I discuss theme three.

### 6.1.2 Theme Two – Screening is never “good” but what makes our experiences more positive or negative?

Theme two sheds light on trans+ participants experiences of attending screening, including gender dysphoria, physical pain, sexual trauma and issues relating to the health system such as health professional’s attitudes and behaviours and systemic barriers. Critically, this theme also highlighted the importance of the interaction of multiple factors. For example, participants reported that gender dysphoria can be influenced by mistreatment from health professionals or experiences of sexual assault, which can heighten emotional distress. Further, these experiences can also interact to increase concern about whether health professionals will treat trans+ patients appropriately. For example, participants who have experienced transphobic or ableist microaggressions or discrimination, or who have disclosed trauma to health professionals who do not treat this seriously or sensitively, may anticipate that they will be treated in a similar manner at future health appointments. This can have a cumulative impact on experiences of cervical screening. Therefore, it is inappropriate to consider each factor affecting screening experiences separately as they intersect to exacerbate distress, and considering one at a time would not capture a comprehensive understanding of individual experiences of screening. Therefore, I argue that it is vital to consider how different elements of a persons’ identity and previous experience may contribute to discomfort during cervical screening.

#### Participant’s experiences of physical pain

As discussed in theme one, trans+ people anticipate pain during cervical screening. Multiple participants in this study experienced physical pain, with some being so severe that they require sedation to undergo the procedure. Previous empirical research has reported that testosterone use can be a cause of additional pain for trans+ people (Connolly, Hughes and Berner, 2020; Weyers *et al.*, 2021). Two participants discussed the impact of testosterone on their cervical screening experience. Participants who have since started testosterone shared their apprehension towards attending future screening following this, due to the potential for increased pain and due to worries about how health professionals will respond to their changing body. From the findings, testosterone use had led to vaginal dryness for many participants which created increased pain during the screening procedure. This has in part led to one participant’s need to be sedated for screening. Some participants also linked being asexual or not engaging in penetrative sex with experiencing physical pain. Participants disclosed items that helped like additional lubrication and smaller speculums, but it is important to note that health professionals did not always offer these. Some participants were able to lessen this pain through using a small speculum with lubricant, and through feeling comfortable with the health practitioner who was able to reassure them. Previous research has also found that speculum lubrication significantly reduces pain experienced during cervical screening, and that its use does not affect the adequacy of cervical samples (Ilika *et al.*, 2024). Further, the findings reported in this thesis highlight that the experience of physical discomfort can be reduced by feeling comfortable and less anxious with the health professional, which has also been shared by other trans+ people in other studies (i.e. Dhillon *et al.*, 2020). This highlights the importance and impact of health professionals being reassuring and knowledgeable about trans+ health in order to improve trans+ patients experiences of cervical screening emotionally and physically.

#### Health professionals’ impact on cervical screening experiences

Whilst most participants reported negative experiences of screening, two participants reported having positive experiences of screening which they shared were largely due to 1) the behaviours and attitudes of health professionals and 2) the “headspace” in which they inhabited at the time. Multiple participants shared that they needed to feel comfortable in their body and gender, for example through gender affirming care, in order to attend or to have a positive experience of screening. A participant who had not yet attended screening stated that it currently felt impossible to attend screening due to the headspace they were in, but that once they felt more comfortable and affirmed in their body and gender, they would feel more able to attend. This highlights the importance of feeling comfortable in their own bodies. Similarly, another participant reported feeling comfortable accessing screening once they were affirmed in everyday life as they described cervical screening as a relatively small thing that would not impact their or other’s views about their gender. This was also found by Bernstein *et al.*, (2017); in which two participants shared that feeling affirmed and comfortable in their body, and affirmed by people in their everyday life made it easier to attend screening due to being accepted and confident in their gender. In contrast, one participant shared that they were not accepted by family and this created fear that the health professional would see their body as “grotesque or sinful” due to this being their previous experiences of coming out (Bernstein *et al.*, 2017). This therefore highlights that trans+ patients’ comfort in their gender and bodies, and how they have been treated by other people, can impact their experiences of cervical screening, as well as willingness to attend.

Health professionals play an important role in influencing trans+ participants experiences of screening. Participants who had a knowledgeable, reassuring and understanding health professional reported more positive experiences than those who had less knowledgeable, experienced or reassuring health professionals. Patients reporting more positive experiences of cervical screening when health professionals show respect and sensitivity towards their gender identity, for example by using the correct name, pronouns and terminology and not making inappropriate comments about their identities or bodies has been consistently reported across empirical studies (Semlyen and Kunasegaran, 2016; Dhillon *et al.*, 2020; Johnson, Wakefield and Garthe, 2020). For example, in a scoping review of 15 research studies across the US, UK and Canada, Dhillon *et al.*, (2020) demonstrated the profound impact that health professionals can have on patient experience, such as patients who reported having practitioners who affirmed their gender stated that this helped to reduce discomfort, and sometimes reduced dysphoria. This thesis further supports this point, for example, one participant shared that they felt less emotional discomfort and physical pain during their second screening appointment as they knew that the health professional which would undertake the screening would be knowledgeable and reassuring, which helped to lessen anxiety surrounding this appointment. This participant believed that the health professional was a large part of their comfort. Further, both two participants were comforted by their health professionals being aware of barriers to accessing cervical screening for trans+ people, or how hormone therapy may impact screening experiences. For example, participants shared that they believe their appointment would not have been positive if not for having a reassuring and knowledgeable health professional. Participants also shared that they would request the same health professional again in instances where this was a positive experience.

In contrast, participants who were screened by health professionals who were less knowledgeable, less open or less reassuring reported negative experiences, including in some cases not wanting to reattend. For example, some health professionals were unaware of what the term “non-binary” meant. This highlights a clear disparity in health professionals’ knowledge about trans+ health, as some health professionals lacked basic knowledge of trans+ identities whereas others were knowledgeable about trans+ specific health needs and shared knowledge that the participants themselves were unaware of. It is important that trans+ patients feel they are respected and safe, for example being familiar with terms relating to trans+ identities including not using outdated terms and respecting patients names and pronouns as using incorrect terms may lead to a loss of trust with the health professionals (Vincent, 2018b). Additionally, it is clear from the thesis findings that having more than basic knowledge of trans+ specific health helps to create a more positive provider-patient relationships, which leads to more positive experiences of health services, recommendations for this are discussed within Chapter 7: Implications. This was also reported by Harb *et al.*, (2019) who found that trans+ people are more comfortable with cervical screening when providers have knowledge of providing screening to trans+ people, feel comfortable treating them and were able to reassure trans+ people.

Additionally, some participants felt it was necessary to hide their identities due to worries about having uncomfortable conversations and whether this disclosure would impact how health professionals treated them. For example, a participant shared that they hide their identity and behaviours during health appointments to appear to health professionals as “normal” and similar to other patients they treat; being cisgender and heterosexual. Previous anecdotal literature highlights that this is not uncommon among trans+ people:

“Too often, queer and trans people seeking to access health care are required to apply a veneer of “normalcy” and “respectability” to our lives and bodies to achieve a form of conditional acceptance inside a system that wasn’t designed for us” (Sharman, 2021:p57).

As above, trans+ people often feel they must look and behave a certain way in order to combat anticipated stigma, discrimination or mistreatment from health professionals. For many, this included hiding their gender identity. Further, some participants shared concerns about how health professionals will respond to their changing bodies from gender affirming care, such as lower growth from testosterone use. Participants were anxious that this may impact how they are treated due to their perception that the health professional will lack understanding. Trans+ patients report feeling more comfortable when providers are experienced with caring for trans+ bodies, which differ from the binary male or female bodies which are the main, or sometimes only, bodies shown during medical training (Dhillon, *et al.*, 2020). This limited exposure to trans+ bodies created anxiety among some participants, thus highlighting that gender affirming care itself can lead to further anxiety about their treatment within health services such as cervical screening by creating an additional layer of anxiety about how health professionals will view their bodies. This contrasts experiences of participants who felt more comfortable with attending cervical screening due to gender affirming care, which further highlights the heterogeneity of trans+ health experiences, and the complexities involved in these. Therefore, ensuring that training for health professionals includes sharing bodies which may differ from the traditional gender binary may help trans+ people to feel more comfortable accessing healthcare, and may reduce judgement from health professionals by ensuring a trans patient is not the first time they have seen a trans body. This should include transmasculine and transfeminine people at various stages of medical transition, including how medical transition can look different for different people and that some trans+ people may not want to transition at all.

#### Sexual trauma & cervical screening

A previous history of sexual trauma has been highlighted as a significant barrier to screening among both trans+ and cisgender populations due to the emotional discomfort which may arise during screening (Reisner *et al.*, 2017; Gibson *et al.*, 2021). Some participants shared that their previous experience of sexual violence had a profound impact on their experience of cervical screening. For example, some participants shared that cervical screening was reminiscent of their experiences of sexual violence or made them feel as though they were reliving it. Trans+ people are more likely to have experienced sexual violence than cisgender men and women (Johnson, Wakefield and Garthe, 2020). For example, the US National Crime Victimization Survey found that transgender people are four times as likely than cisgender people to have experience violent victimisation, including sexual assault and rape (Flores *et al.*, 2021). Understanding how sexual trauma impacts experiences of attending or choosing not to attend screening is necessary to create modifications which may improve screening uptake and experience. Although a history of sexual trauma is a significant barrier to cervical screening for both cisgender and trans+ people, sexual trauma may impact trans+ people and their experiences of screening in different ways to cisgender women. For example, cisgender women reported that undergoing cervical screening can cause them to relive sexual trauma, feel out of control, vulnerable and discussed difficulties with the use of the speculum (Cadman *et al.*, 2012). This is similar to experiences of trans+ people reported both within this study and in previous research such as (Bernstein *et al.*, 2017; Johnson, Wakefield and Garthe, 2020; Gibson *et al.*, 2021). For example, one participant in the study by Johnson, Wakefield and Garthe, (2020) had tried multiple times to attend cervical screening but cancelled each time due to significant fear and anxiety relating to their sexual trauma, which is similar to experiences of cisgender women outlined by (Cadman *et al.*, 2012). However, trans+ people have additional factors, such as gender dysphoria being triggered from the focus on anatomy, which may intersect with experiences of sexual trauma to produce worsened experiences. Therefore, it is important to consider how being trans+ and a survivor of sexual assault affects experiences of and willingness to attend screening.

Participants with a history of sexual violence shared that they felt a loss of control, were worried that health professionals would not stop when asked to, and felt the speculum was especially triggering. Further, participants shared that having experienced sexual assault created additional difficulties when considering attending screening and led to delaying screening appointments or feeling heightened anxiety before the screening appointment. Similar experiences have been reported across the literature as trans+ survivors of sexual assault often discuss difficulties of being touched by a stranger, worrying that the clinician may ignore them if they become too distressed and request the procedure to stop, and also report sexual trauma as a factor for non-attendance (Bernstein *et al.*, 2017; Johnson, Wakefield and Garthe, 2020; Carroll, *et al.,* 2023). For example, through analysing the questions about cervical screening in the *Counting Ourselves: Aotearoa New Zealand Trans and Non- Binary Health Survey* Carroll *et al.*, (2023) found that trans+ survivors of sexual assault had increased fear and anxiety surrounding the insertion of the speculum. Carroll *et al.*, (2023) also found that for some trans+ people, their experiences of sexual trauma prevented them from attending screening.

The findings of this thesis also show that being asked to say the word “stop” to request the procedure to end can be similarly triggering of previous sexual trauma. For example, one participant reported worries that asking health professionals to “stop” and this being ignored was reminiscent of times where they had asked their abusers to stop and this had not happened, which created discomfort in using the word “stop”. Therefore, this participant suggested that the use of a safe word with less emotions attached to it may help to ease the difficulties of requesting the procedure to end.

Additionally, some participants shared that the way in which health professionals respond to disclosures of previous sexual assault can impact how comfortable and safe they feel during the appointment. Participants reported multiple negative responses from health professionals upon disclosing their history of sexual trauma, which has impacted trust in medical professionals to provide participants with adequate care. For example, one health professional told a participant that the sexual trauma should not impact him anymore because it happened before the health professional was born. This made the participant feel unsafe and highlights the need for health professionals to undergo training on supporting survivors of sexual assault. Multiple participants within this study stated that health professionals who undertake invasive procedures such as cervical screening should be trauma informed, and this has been reported in previous literature (Gatos, 2018; Gibson *et al.*, 2021). However, it is clear from this thesis that health professionals may not understand the impact of trauma on cervical screening or know how to care for survivors in an appropriate and reassuring manner.

Theme two also sheds insight on disabled trans+ peoples experiences of cervical screening. The majority of participants described themselves as having a disability and some discussed the impact of this on screening. For example, participants who had medical conditions shared that these conditions made screening more painful, which sometimes led to abandoning cervical screening multiple times. However, participants had differing responses from the health professionals which further highlights the influence that health professionals can have on providing care. For example, some participants felt their pain was not taken seriously, and they were not reassured or offered potential relief from this pain such as taking a break or using a smaller speculum. In contrast, one participant became determined to provide an adequate sample and was able to work with their health professional to undertake a successful screening by trying multiple different speculums, positions and by talking through the procedure. This highlights that provider willingness to reassure patients and try multiple different methods for undertaking cervical screening has a direct impact on how participants feel during and following screening, as well as the ability to successfully provide a sample.

Previous research has suggested that being transgender and having a disability can increase patient disempowerment in medical interactions (Bernstein *et al.*, 2017) and facing barriers such as ableist or transphobic microaggressions (Lamba *et al.*, 2023). Further, trans+ people with disabilities report higher rates of mistreatment by healthcare providers compared to trans+ people without disabilities (Mulcahy *et al.*, 2022). This was also experienced by participants within this study, for example, health professionals often spoke to a disabled participant’s parent or carer, which led to frustration as this participant was capable of discussing his own medical wishes without external input, but this option was revoked by health professionals. Further, a disabled participant shared that health professionals were often more focused on asking questions about the participants disabilities and trans+ identity rather than on undertaking the procedure. Whilst it may be beneficial under person-centred care for health professionals to have a better understanding of how disability or trans identity affects screening impacts, this should be done in an appropriate manner underpinned by respect and communication about how these may influence the procedure and what can be done to improve this, not curiosity. Further, this participant felt that the questions had negative undertones, for example he felt that the health professional was insinuating that his transness was a phase due to asking how long he intended to be trans for. Disabled participants also felt that their difficulties with cervical screening were conceptualised by health professionals as being part of their disability, rather than recognising other factors which create distress such as the reminder of sexual trauma. For one participant, this felt like the health professionals were not able to see him past his disability, which led to him feeling ignored and misunderstood whilst struggling with the screening procedure as a trans+, disabled survivor of childhood sexual abuse.

There are often also physical barriers for wheelchair users when trying to attend cervical screening. In a research project which surveyed 335 women with disabilities’ experiences of cervical screening, Jo’s Trust, (2019) found that 63% of participants had been unable to attend cervical screening due to their disability. Reasons for this were physical pain from the speculum, not being able to get into a comfortable position, as well as systemic barriers such as 43% of women reporting that their GP was not wheelchair accessible, and only 1% of GP services had a hoist, without which it is difficult for disabled patients to get into a screening position (Jo’s Trust, 2019). This creates a disempowering environment for disabled people, including trans+ people with disabilities, thus creating a further barrier to cervical screening that is not experienced by trans+ people without disabilities, which highlights the importance of elevating disabled voices within trans+ (and all) health research.

Additionally, just over half of the sample described themselves as being neurodivergent, including having autism, ADHD and/or borderline personality disorder, which also creates additional barriers to accessing healthcare. For example, a Canadian study of 40 adults with autism reported that 47% of participants had negative experiences with health services, 47% felt overwhelmed by the steps to accessing care, and 53% felt they were unable to describe their health needs, which impacted their access to and experience of health services (Vogan *et al.*, 2017). With regards to cervical screening, hypersensitivity to touch can make accessing this service more difficult for autistic women (Zerbo *et al.*, 2019). There is also a significant discrepancy in screening uptake among cisgender women with and without autism, for example a US study found that 38% of cisgender autistic women had ever accessed cervical screening, compared with 72.5% of cisgender women who were not autistic (Chen *et al.*, 2024). It is likely that a similar discrepancy exists with trans+ autistic people, although no research has been undertaken in this area (Khan and Richardson, 2022). Further, research has shown that there is a higher prevalence of autism among trans+ people (Adams *et al.*, 2024). Additionally, there is a paucity of research concerned with neurodivergent trans+ peoples experiences of health services such as primary care, mental health services or gender affirming care (Adams *et al.*, 2024). Adams *et al.*, (2024) found that autistic trans+ individuals experience ableist and transphobic discrimination and significant disparities in access to primary care, mental health care, and more negative health outcomes which highlights the need for changes to how trans+ autistic people are treated within health settings. Further, an international study with participants from the UK, US, Canada, Australia, Germany, Norway and the Netherlands found that health professionals often lack knowledge of providing appropriate care for people who are transgender and people who are neurodivergent, and thus trans+ neurodivergent people can suffer from being doubly misunderstood by health professionals which can impact healthcare access and experiences (Bruce, Munday and Kapp, 2023). As discussed throughout this thesis, previous negative experiences with health service can impact uptake and experiences of cervical screening, and it is therefore likely that neurodivergent trans+ people experience additional challenges to accessing and attending cervical screening.

It has been argued that cervical screening can be particularly challenging for neurodivergent people due to the invasive nature of the procedure and physical and emotional discomfort caused by this (Khan and Richardson, 2022). Health professionals may have a limited understanding of neurodiversity, as discussed above, means they lack understanding of the way that conditions such as autism may impact patient experiences of medical procedures such as cervical screening (Khan and Richardson, 2022). Additional difficulties also exist within cervical screening for trans+ autistic people (Khan and Richardson, 2022). For example, health professionals also commonly lack understanding of trans+ health needs, which may intersect with health needs of neurodivergent people to produce worse outcomes for trans+ neurodivergent people. The limited research in this area means that supports that may help neurodivergent trans+ people may be lacking, and patients may feel misunderstood and unable have their needs supported by their HCPs.

The findings of this thesis highlight a number of challenges faced by neurodivergent trans+ people when attending cervical screening. For example, individuals may experience sensory overload in clinical settings due to the bright lights and loud noises. Further, they may experience pain sensitivity due to being autistic, which means they feel extreme pain undergoing cervical screening and have to be sedated for this. Experiencing pain differently to neurotypical people is a common autistic quality, such as experiencing hypo/hypersensitivity to pain or having differences in how pain is understood (interoception), which can be a barrier to attending screening due to the discomfort caused by the speculum (Khan and Richardson, 2022). Participants shared strategies, discussed in Chapter 7 Implications, which they used to manage cervical screening as neurodivergent trans+ people.

Theme two therefore highlights the heterogeneity of trans+ experiences of cervical screening, which are influenced by a range of different factors such as previous experiences in health services, feelings of gender affirmation/dysphoria, a history of sexual trauma, health professionals’ knowledge, attitudes and behaviours and having a disability. A comprehensive understanding of patient experiences of attending cervical screening requires considering the interaction of multiple factors which influence screening appointments.

### 6.1.3 Theme Three – Relief or regret: participants thoughts and experiences following screening appointments

To my knowledge, this thesis provides the first in-depth account of trans+ participants thoughts, feelings and experiences following cervical screening appointments. There is also a dearth of literature discussing cisgender women’s thoughts, feelings and experiences following cervical screening appointments, including when screening procedures were abandoned or incomplete. As discussed in theme three, trans+ people feel various emotions following successful screening appointments (which refers to appointments in which a sample was collected), from relief that they have provided a sample and the screening process is now over for three more years, to distress that they had to attend screening and continuing to feel dysphoria and emotional upset afterwards. It is important to understand the emotional impact of screening appointments to provide better support for trans+ people following cervical screening to improve experiences of screening and increase future reattendance.

Within this thesis, some participants reported feeling intense distress following the cervical screening procedure. For example, participants reported feeling physical pain or discomfort, bleeding and heightened gender dysphoria after the appointment. These elements can also interact to increase distress, for example a participant in a US study shared that they bled and felt pain for two days following the cervical screening appointment, which caused heightened gender dysphoria due to the reminder of menstruation (Bernstein *et al.*, 2017). This participant also reported that the health professional refused to stop the procedure when they said it was too painful, which created additional distress following the appointment. Participants within my PhD research also reported that health professionals’ behaviours can influence how they feel post-screening, for example one participant was told that their genitals were “traumatised” from the procedure, which created further discomfort following a procedure they found physically painful and emotionally distressing. Participants reported coping strategies for this, for example by making plans to help to realign themselves with their gender, such as wearing binders when they usually would not, or booking gender affirming care following the appointment. Participants felt that doing something affirming was necessary to balance the discomfort from attending cervical screening.

In contrast, other participants felt relieved that the screening appointment was over, that they could be reassured that they were healthy, and that they would not have to attend for three years. These participants reported no negative emotional impact following screening and were able to continue with their day uninfluenced by the appointment. A phenomenological study in Norway involving 13 women aged 16-80 who had undergone various vaginal examinations also found that despite anxiety before and during the procedure, participants felt an emotional benefit and reduced health anxiety once the appointment was over as they could feel reassured that they were physically healthy (Larsen, Oldeide and Malterud, 1997). Within this thesis, participants were able to feel relieved or neutral following the screening appointment when they had had a positive experience with the health professional and had felt a small level of physical pain. For example, participants who reported that their health professional listened to their concerns and offered support felt less of an emotional impact following screening than those who felt ignored or misunderstood by health professionals. Further, participants who had had a previous negative experience were more likely to skip or delay future screening appointments due to increased anxiety or fear.

Trans+ people who were unable to provide a sample reported varied strong emotions about this, including disappointment that they had to go through the procedure but will not have the benefit of more knowledge about their health, to determination to reattend screening and provide an adequate sample. Multiple participants within this thesis blamed themselves for being unable to complete cervical screening and pointed to elements about themselves and their identity to explain why this happened. For example, trans+ participants referenced blaming the type of sex they engaged in, their lack of sexual activity, their body for being “not normal” referring to having an anti-retroverted cervix, and even the clothes they wore as reasons for their unsuccessful screening appointment. To my knowledge, no previous research discusses the impact of abandoning a cervical screening appointment due to being unable to provide a sample, such as due to physical or emotional discomfort. Instead, previous research about patients’ thoughts, feelings and experiences post-screening focus on cases where the screening appointment led to inadequate samples, meaning that the laboratory the sample was sent to was unable to discern results from the sample for various reasons. Following disclosure of the inadequate sample, patients are invited to reattend cervical screening to provide a second sample to be screened. A UK based questionnaire which compared the experiences of 180 women who received an inadequate screening result with 226 women who received a normal screening result found that getting an inadequate screening result increases anxiety about the results, their likelihood of developing cervical cancer, and reattending screening (French, Maissi and Marteau, 2004). Further, women who reported higher anxiety levels were less likely to repeat their screening within the recommended time frame, resulting in 81% of participants reattending to get there result which meant that a significant amount of women did not reattend (French, Maissi and Marteau, 2004), thus effectively skipping cervical screening due to not having a result. The association of anxiety with reduced likelihood of reattendance highlights the need to ascertain how this anxiety can be avoided (French, Maissi and Marteau, 2004). A scoping review of cervical screening among trans+ people also found that trans+ people are consistently more likely to provide inadequate samples (Gatos, 2018), which highlights the need to understand how inadequate samples influence trans+ peoples experiences of screening and willingness to reattend in the future.

### 6.1.4 [Theme four - Making screening more manageable: recommendations for improving cervical screening for trans+ people](#_Toc168398581)

Theme four focused upon ways which trans+ peoples experiences of cervical screening may be improved and identified the importance of choice, potential modifications to the procedure, improving medical education and training, de-gendering cervical screening and the importance of community in coping with cervical screening. This section provides a short discussion of theme four in order to prevent overlap with Chapter 7: Implications due to the nature of this theme.

Participants’ desire to be given more choice, feel respected, and be seen as an individual rather than a ‘check box’ for the health professional was an important element across theme four. This sentiment has also been discussed in previous research, such as Peitzmeier *et al.*, (2017) which reported that trans+ people felt dehumanised and deindividualised when health professionals were unwilling to communicate or adapt the exam to their needs, thus preferring to be given choices about the procedure. To begin discussions about potential improvements, participants were asked their opinions on several potential modifications (as discussed above: using a smaller speculum, self-insertion of the speculum and bringing a trusted friend) to understand how trans+ people may feel about modifications which have been proposed in previous literature. Participants then shared their own ideas for improving cervical screening, such as providing more choice for example by amending questions which are asked prior to the procedure starting, the importance of improving health professionals understanding of trans+ people, and coping strategies used by neurodivergent participants to manage overwhelm during screening.

Participants within this thesis had varying opinions on modifications to the procedure, but each shared that they thought any changes which may improve screening for others should be offered. For example, some participants stated that they would try self-insertion of the speculum as a method of having more control over the procedure, however others were worried that they would do it wrong or simply did not like the idea of this. Further, small changes to the procedure, including using a smaller speculum, self-insertion, or bringing a trusted friend had been offered to some but not all participants, which shows that modifications which may improve screening experiences are not widespread across the North of England. For example, many participants disclosed that they had used a smaller speculum and found that this reduced the pain, however others, including those who had significant pain, had never been offered this. It is vital to ensure that smaller speculums are offered to those experiencing pain, or who are anxious about the speculum for various reasons, as it is clear that this is an option available from some health professionals and thus is an appropriate method of reducing pain and/or anxiety, but has not been provided throughout the NHS. Previous studies have also highlighted the importance of making small changes to the procedure in order to improve cervical screening experiences. For example, a systematic review looking at ways to improve cervical screening for women with disabilities found that multiple guidelines suggested that ensuring that women were familiar with the equipment, such as the speculum, and discussing different positions which the patient could be in may help to reduce pain and anxiety around cervical screening (Kuper *et al.*, 2024). Further, Peitzmeier *et al.*, (2017) found that trans+ people felt more comfortable during screening when practitioners modified the exam, for example by allowing the patient to insert the speculum themselves or prescribing anti-anxiety medication. Therefore, it is clear that small modifications can improve trans+ peoples experiences of cervical screening.

The findings also highlighted that trans+ people wanted health professionals to have a better understanding of trans+ identities and health needs. Participants disclosed that having to explain what being trans+ or non-binary meant was frustrating and a barrier to accessing cervical screening as not understanding what these terms mean is an indicator that health professionals may not be understanding or sensitive to trans+ people. The desire for health professionals involved in cervical screening to have better understanding of underserved groups has also been echoed by various studies, for example sexual minority women and trans+ people in Aotearoa (Ellis, 2024), an international systematic review of women with disabilities (Kuper *et al.*, 2024) and migrants from Nigeria, Ghana, Kenya and Cameroon living in Finland (Idehen, Pietilä and Kangasniemi, 2020). A key element of each study was the importance that the participants placed on health professionals having an understanding of their background. For example, Kuper *et al.*, (2024) found that many of the women in this study had experienced ableism from health professionals, which resulted in a lack of trust and was a barrier to reattendance. Participants in this study expressed the need for health professionals to undergo education or training to improve their understanding of disabilities, how to provide adequate care for people with disabilities, and to understand why people with disabilities may find screening difficult. These areas of education were also highlighted by this thesis, as participants in this study desired improved understanding of trans+ identities, how to care for trans+ people, and an understanding of why trans+ people may find screening difficult in order to provide appropriate and sensitive care for trans+ people. Further, a systematic review of international guidelines for transgender health revealed that each of the 14 guidelines referenced the importance of improving education and training for health professionals (Nicholls *et al.*, 2023). However, there was limited discussion of people with multiple marginalised identities within the guidelines and therefore improving guidance for cervical screening which recognises people with multiple marginalised identities would strengthen the guidance identified in the review (Nicholls *et al.*, 2023). Due to the diversity among trans+ people, improving experiences of health care such as cervical screening requires improving health professionals understanding of trans+ identities and experiences, but also of other marginalised characteristics to ensure that trans+ people are not met with other discriminatory or stigmatising experiences. Further, participants within this project stressed the importance of health professionals involved in cervical screening to undergo training in trauma informed care. A more in-depth discussion of the education that trans+ participants suggested is provided in Chapter 7: Implications.

Trans+ people also expressed their desire for cervical screening to be de-gendered. Participants pointed to benefits they themselves would feel from this, such as reduced gender dysphoria and feeling like they were welcome/belonged in health services, whilst also recognising benefits to other groups. For example, participants disclosed that they were aware of cisgender women who had had hysterectomies but continued to receive an invitation to cervical screening, which caused distress due to the reminder of this surgery and the potential reasons for it. Additionally, transfeminine people who are registered as female within health services may be sent cervical screening invitations despite not needing this service, which may cause heightened gender dysphoria (Vincent, 2018b). Therefore, moving the focus of cervical screening as something for women towards being something for people with a cervix would benefit cisgender and trans+ people by ensuring the automatic invitation system doesn’t cause harm by sending invitations to those who do not require the service.

Overall, this section demonstrates the need for trans+ people to be given equitable care, which is equal but not identical to that of cis women, as trans+ people should be able to access screening but have different needs to cisgender women (Caulfield et al., 2016). Many of the improvements suggested by trans+ people may also be useful to other groups, such as cisgender women who are fearful of screening, to empower them to take more control of how the procedure is undertaken and to reduce anxiety around screening.

## 6.2 Contributions to knowledge

This thesis makes two important contributions to the knowledge around trans+ experiences of cervical screening. Firstly, this thesis highlights the importance of using intersectionality in trans+ health research by demonstrating how having multiple marginalised identities can contribute to poorer experiences of health services. Secondly, the use of a novel approach allowed greater insight into trans+ peoples experiences of cervical screening by ensuring participants engaged in a method in which they felt comfortable enough to discuss their experiences in depth, and which allowed discussion between the researcher and participants to elicit further details about participants experiences. These contributions to knowledge are important as they allowed a deeper, richer understanding of the complexities of trans+ experiences of cervical screening through taking a qualitative and intersectional approach.

### 6.2.1 Contribution one: The importance of intersectionality in trans+ research

This thesis draws attention to the importance of recognising diversity in trans+ health experiences through highlighting how living at the intersection of being trans+ and having one or more other marginalised characteristic impacts both decisions to attend and experiences of cervical screening. Specifically, this thesis advances knowledge within the intersection between disability, asexuality and being trans+. By exploring how intersections of disability, asexuality and being trans+ may affect experiences of cervical screening, I argue that this thesis draws attention to recognising diversity among trans+ people and how this may impact their experiences of health services.

Previous research on trans+ health often discusses trans+ people as a homogenous group, thus ignoring factors which may influence trans+ experiences of health such as ethnicity/race or disabilities (Fish, 2017). Therefore, as discussed in the methodology chapter, a key aim of this thesis was to use intersectional theory to explore trans+ peoples experiences of cervical screening. Using intersectional theory within health research provides a framework for a more comprehensive understanding of patient health and healthcare needs by considering how experiences may be different for those with multiple intersecting identities (Fish, 2017). This involves consideration of diverse identities and how the sociocultural factors associated with each marginalised identity can affect health experiences, including patient-provider interactions, access to health services, and health outcomes (Fish, 2017). A key element of intersectional theory is working towards social justice and equity, which can only be achieved by understanding the root causes of health inequality and developing and implementing ways to improve this. Thus, using an intersectional approach to health research is important in developing meaningful improvements.

A key element of this contribution to knowledge is the attention paid to trans+ people with disabilities and how their experience may be different to those without disabilities. To my knowledge, this is the first study which discusses disabled trans+ peoples experiences of cervical screening. As above, overlooking how trans+ people may also have other marginalised characteristics means that trans+ and disabled people are often treated as separate groups whilst ignoring the existence of trans+ disabled people (Kermode, 2019). Trans+ people with disabilities including mental illness or psychiatric disability, chronic illness, physical disability, neurological condition, sensory disability, intellectual or cognitive disability, and/or developmental disability reported in an online survey having more unmet health needs than trans+ people without disabilities, which may reflect the compounding effects of disability and trans+ identity on access to and experiences of health services (Mulcahy *et al.*, 2022). Therefore, this thesis highlights how disabled trans+ people experience cervical screening differently from those without disabilities. Using an intersectional lens, this thesis is able to explore how experiences of power collides, interlocks and intersects as described by Crenshaw, (2017). For example, it highlights the impact that being trans+ and a wheelchair user has on cervical screening, such as being ignored by health professionals who elect to only talk to those accompanying the participant, or inappropriate behaviour such as treating a disabled participant who was uncomfortable due to their history of sexual trauma as a “naughty misbehaving disabled person” rather than someone who was uncomfortable. From this, it is clear that Ethans experience and the way in which health professionals approach him are impacted by being both trans+ and disabled. Health professionals viewed Ethan as having limited power, for example by perceiving that he could not speak for himself and thus talking to those accompanying him, or by viewing his discomfort due to his past experiences of sexual trauma as being “naughty” because he is disabled. This thesis also identified the sensory overwhelm which trans+ neurodivergent people experience whilst attending hospitals due to the atmosphere, and during cervical screening due to the differences in pain perception among neurodivergent people. Trans+ disabled and neurodivergent people must also contend with issues which arise due to their trans status, such as their gender identity not being understood or respected by health professionals, and gender dysphoria from the focus on anatomy. This thesis therefore highlights that disabled trans+ people face multiple intersecting barriers to attending cervical screening which influence experiences of cervical screening.

Further, the findings demonstrated that trans+ asexual people could experience cervical screening differently to allosexual trans+ people. For example, participants who disclosed their asexual identity had specific worries about how this would affect their screening experience, and both participants experiences of screening were impacted by the health professionals responses to their asexuality. Asexuality is often ignored within the health system, health research, and within the wider LGBTQ+ community, which leads to a lack of understanding of asexuality among health professionals (Benoit and De Santos, 2023). Through exploring how trans+ asexual people experience cervical screening, this thesis has contributed to the limited knowledge of trans+ asexual peoples experiences of health services. The limited inclusion of asexual people in research is not restricted to health research but is widespread over multiple areas. For example, asexual activist Yasmin Benoit undertook a report with Stonewall titled Ace in the UK (Benoit and De Santos, 2023) to understand asexual peoples experiences of living in the UK to combat the lack of inclusion. A section of this looked at health experiences, including reproductive health services such as cervical screening. Within this research, all participants reported that a lack of awareness of asexuality had negatively impacted their health experiences (Benoit and De Santos, 2023). This was also reported by participants in this research study, for example, when one participant shared their asexuality with the health professional they were told “oh but I want you to lose your virginity to someone special”. This made them feel so uncomfortable that they requested a change of nurse.

Asexual people have also been historically mistreated in health services, as evidenced by the Ace in the UK report which highlighted that upon coming out as asexual, the focus became upon viewing asexuality as a symptom which needed to be fixed, such as being the result of anti-depressant use or previous trauma, rather than viewing it as a valid identity (Benoit and De Santos, 2023). Therefore, improving the body of literature on asexual health focusing on asexual people’s experiences, as has been done within this thesis, rather than those upheld by the medical systems may lead to developing trust in health systems in providing appropriate care for asexual people. Further, negative experiences with health professionals and the neglect to consider asexual identities in policy and practice creates distrust (Benoit and De Santos, 2023), which in turn may make accessing cervical screening more difficult. The extent to which asexual people feel mistrust within health services therefore may impact their screening experiences, which, when coupled with the mistrust that trans+ people harbour may mean that asexual trans+ participants have worse experiences of cervical screening. As stated within the implications chapter, it is vital that more health research considers the experiences of asexual people.

Therefore, regarding trans+ health experiences, this thesis adds to the body of empirical literature by highlighting the importance of considering intersectionality within trans+ experiences and the heterogeny of the trans+ community. Exploring disabled trans+ and autistic trans+ experiences of cervical screening has enabled a deeper understanding of barriers impacting their experiences of cervical screening than previously. Building a more intersectional body of literature surrounding trans+ experiences may lead to the development of more appropriate improvements to health services by ensuring that trans+ people are not met with ‘one size fits all’ solutions to improving experiences, but rather individual differences are taken into account and trans+ people are given autonomy and choice in what they believe will improve their own experiences of cervical screening, and thus willingness to reattend.

### 6.2.2 Contribution two: the use of inclusive and sensitive methods to elicit trans+ peoples experiences of cervical screening

This thesis also provides a methodological contribution to the understanding of trans+ experiences of cervical cancer screening. The use of a novel, qualitative approach allowed a broader and deeper understanding of trans+ peoples experiences of accessing cervical screening by giving participants the option to share their experiences in detail and in a way which felt most comfortable to them. Furthermore, this thesis considers cervical cancer screening experiences of trans+ people who live in the North of England and who are not connected with trans specific clinics. Therefore, it provides two important methodological contributions: furthering qualitative understandings of trans+ peoples experiences of cervical screening using a novel approach, and understanding experiences of trans+ people who live in the North of England and are not connected with trans+ specific clinics.

Despite the importance of quantitative research in highlighting the issue of trans+ cervical screening disparities, qualitative research is required to understand the underpinnings of these disparities in order to develop recommendations to improve cervical screening experiences, and thus the uptake of cervical screening among trans+ people. For example, the use of a qualitative method means this thesis is able to provide a discussion of different factors influencing screening experiences and the interaction of multiple factors, rather than viewing these individually and with minimal detail of how they feel for participants themselves. Through the use of two methods, semi-structured interviews and an online asynchronous focus group, as described in Chapter 4: Methods, I was able to elicit deeper insight into trans+ peoples experiences of accessing cervical screening and thus provide a more detailed analysis and interpretation of their experiences. For example, I was able to explore the complexities of deciding to attend cervical screening and experiences following appointments, barriers and facilitators which impact experiences of screening, and discuss any changes which may improve trans+ experiences of screening, including reasoning behind this to create a more comprehensive understanding of this. Further, the use of this method allowed discussion of how these factors interlink, which may have been missed if using quantitative methods, or other qualitative methods such as open text surveys which restrict the researcher’s ability to probe for more detail. Therefore, this approach enabled me to provide a deeper and broader analysis of trans+ experiences of cervical screening and the complexities within these that may not have been reached otherwise.

Further, offering two ways to participate within this study and enabling trans+ participants to decide which they preferred helped trans+ people feel more comfortable in talking about a sensitive topic. This approach is novel in the area of cervical cancer screening for trans+ people. Ensuring that trans+ participants in research feel comfortable is especially true due to the current political climate of hostility towards trans+ people. The rise in anti-trans rhetoric, legislation and media affects trans+ peoples everyday lives, including mental health and willingness to attend health services (Smith, 2022) and therefore may also impact trans+ peoples willingness to take part in health research. Allowing participants to choose a method with which they felt comfortable may have contributed to participants talking about their experiences despite the impact of the current political climate towards trans+ people. Offering two methods which participants can pick between depending on their personal context may be vital in ensuring trans+ people continue to feel comfortable discussing their experiences of being trans+ in a society that is becoming increasingly hostile towards trans+ people. Thus, the method used within this thesis is an important methodological contribution due to offering deeper insight into experiences, which allowed for the co-construction of findings between myself and the participants through analysis of their experiences with my own interpretations, and for allowing participants to feel comfortable in the current political context.

Finally, as evidenced in the literature review, there is currently a lack of qualitative research exploring trans and non-binary people’s experiences of cervical cancer screening in a UK context. The majority of the research published in the UK is quantitative and undertaken in the South of England, often by recruiting trans+ participants from trans+ specific services. To date, there has been one mixed method study which explores trans+ experiences of cervical screening (Berner, Connolly, *et al.*, 2021). This study used a semi-qualitative survey and participants were recruited through LGBTQ+ specific organisations and Jo’s Trust, which required participants to be connected to these organisations. Therefore, this thesis is novel due to its use of interviews and an online, asynchronous focus group which allowed greater expansion on thoughts and experiences, and the recruitment method and participant group. The use of social media to recruit for this PhD study meant that participants did not have to be connected to LGBTQ+ organisations, and being exclusively in the North allowed the experiences of those not connected with trans+ specific clinics to access cervical screening to share their experiences of attending at GP services or general hospitals which may not have the same level of knowledge or experience of working with trans+ people.

## 6.3 Strengths, limitations and reflexivity

This section explores the quality of this thesis and its findings through discussing the strengths and limitations. Next, I provide an in-depth reflexivity section based on my reflective diary, which explores power in research, positionality, insider/outsider status and various processes which influenced my thought-processes and decision making throughout this study.

Assessing the quality of qualitative research is highly debated within academia as it is difficult to discern what counts as quality within this area, and how to evaluate it (Leung, 2015; Yadav, 2022). Due to the diversity of qualitative research, Yadav (2022) argues that the development of a singular quality criteria framework is not feasible or appropriate to assess quality. Therefore, I take the position that following a singular framework or checklist is not an appropriate method of assessing quality of qualitative research, as it may assess qualitative research based on criteria which may only apply to quantitative research. For example, some frameworks have attempted to apply the quantitative criteria of “inter-rater reliability” to qualitative research through multiple coding, which refers to multiple researchers coding datasets and considering the concordance between the results to “check” coding strategies and interpretation. Barbour (2001) argues that concordance between these analyses should not be considered a marker of quality due to the complexity of qualitative research data, and due to the influence of researcher’s backgrounds on analysis which means that datasets will never be coded in the same way by independent researchers. Many other quantitative criteria, such as generalisability, replicability and confirmability, have been applied to qualitative research in a way which does not consider the underpinnings of qualitative research and thus should not be used to assess the quality of qualitative research. Thus, whilst keeping in mind the various criticisms of qualitative frameworks, I present a discussion of the strengths and limitations of this PhD thesis.

### 6.3.1 Strengths

When considering quality in qualitative research, the methods and methodology must be examined in order to show that the decisions made are appropriate to the research. For example, researchers should discuss why the following decisions were made, and why they were the most appropriate to use in the research study: a qualitative methodology, the research design, recruitment strategies, data collection and analysis (Leung, 2015). Considering these elements allows the reader to form their opinion on whether the research design is appropriate for the research question, and what weight to give the findings of the research (Leung, 2015). Each of the aforementioned elements are discussed in turn in Chapter 3: Methodology and Chapter 4: Methods. Within these chapters, I argue that I chose the most appropriate research design for a variety of reasons and provide a discussion of each of these decisions. For example, I used a qualitative methodology to allow participants to share their experiences and meanings freely and in their own words, rather than being confined to pre-framed responses associated with quantitative research which may assess the incidence of various pre-decided experiences but not the meanings behind these. I also gave participants the options of being interviewed or joining an asynchronous, online focus group. Providing participants with two options enabled them to decide to participate in a way in which they feel most comfortable, and both methods facilitated the collection of rich, detailed data. However, both methods come with their own limitations, such as the requirement for participants to have access to and an understanding of technology in order to participate in the focus group. Further, participants may feel discomfort with sharing vulnerable and sensitive information with the researcher in an interview. However, as discussed in the methods chapter, the use of both methods may reduce the limitations of the opposite method. Therefore, a key strength in this study lies within the appropriateness of the research design in providing a comfortable way for trans+ people to share their experiences, and which ultimately lead to the development of rich, meaningful findings.

Secondly, assessing the trustworthiness of findings has been proposed as an important element of quality qualitative research. This involves transparency in how the data was used to develop the findings. This research uses reflexive thematic analysis, and an in-depth description of this process is provided in Chapter 4: Methods. Further, Appendices 8-11 demonstrate the analytical process, including how the data was coded and how themes were developed. Finally, I would argue that sufficient data is presented in the form of verbatim quotes to support the findings, interpretations and conclusions from this research to provide evidence that the findings are representative of the participants experiences and meanings they place on them. Therefore, I believe that the analysis undertaken within this study is sufficiently transparent. I also discuss the findings in relation to existing literature, such as the contribution to knowledge, within the discussion chapter. These contributions to understandings of trans+ peoples experiences of cervical screening are a key element of understanding trans+ experiences of health services and developing ways to improve them.

Further, the use of reflexivity within qualitative research is widely accepted as a marker for quality research (Davis, 2020). I kept a reflexive diary and provide a discussion of reflexivity within this work in chapter \_ with regards to power, recruitment, data collection, data analysis and thesis writing. This chapter also discusses a number of strengths and limitations within this study, such as the impact of myself as an insider/outsider within this research. For example, my insider status as a non-binary person provided important strengths within this research study due to the relative ease of developing a rapport with participants, and allowing them to be more certain that the intentions and outcomes of the research were not harmful. Therefore, I believe that the reflection I undertook throughout this PhD study is a key strength of the research.

The use of intersectionality provides a particular strength within this research. For example, the majority of participants reported that they had a disability, which meant that I was able to explore experiences of health services at the intersections of being trans+ and disabled. This provides an important insight into disabled trans+ experiences of cervical screening, and wider health care, which is often not considered within current literature which all too often treats trans+ people as a homogenous group which can only have one marginalised characteristic; being trans. Therefore, the collection of data around disability, as well as disabled trans+ experiences is a strength of this research in contributing to knowledge in the wider field.

### 6.3.2 Limitations

It is also vital to consider potential limitations within research studies. Whilst this PhD thesis provides insight into trans+ experiences of health services, it is important to note that the findings are drawn specifically from these participants only and thus should not be considered transferable to the entire trans+ community. Although transferability was not an aim of this study as it is epistemologically counter-intuitive with qualitative research due to the emphasis on individual experiences and the meanings they place, all research can benefit from having a diverse participant group. Therefore, an important limitation within this thesis is the lack of participant diversity in relation to race/ethnicity. The participant group was overwhelmingly comprised of “White British” participants, with one participant who was “British Japanese” and one “White European”. Different perspectives may have been incorporated through a more diverse participant group, such as the ability to discuss how the intersections of race and being trans+ may affect health experiences. Effort was made to include a more diverse participant group, however my position as a white researcher may have made trans+ people of colour feel uncomfortable with being part of the research. Therefore, this limitation may be improved with future which aims to specifically look at trans+ people of colours experiences, or which has a person of colour on the research team.

Furthermore, although this study had a wider age range than previous research in this area, participants were still relatively young (25-45 years of age) and thus the cervical screening experiences of older trans+ adults are not explored. More diversity in terms of age may have led to interesting insights in older trans+ people’s experiences of health.

Despite the advantages of using asynchronous online focus groups, as outlined in Chapter 4: Methods, there are also a number of limitations of this method. For example, asynchronous online focus groups suffer from a lack of natural conversational flow and interaction between participants which exists in synchronous focus groups (Gordon *et al.*, 2021). Participants in a study of eating disorder prevention for trans+ people disclosed that they would have liked for more discussions with other participants within their focus group (Gordon *et al.*, 2021). Within the focus group conducted for this thesis, there was a small amount of discussion between participants however this was limited as compared to synchronous focus groups and thus this lack of conversational flow may have impeded the depth of discussion. Similarly to the interviews, there were also differences between participants on the level of detail they supplied. Some participants wrote long, in-depth answers about their screening experiences, whereas others wrote shorter responses. As participants were able to select which method they felt more comfortable with using another method may have elicited similar results, however an interview or synchronous focus group may have helped to ease participants with shorter responses into discussing their experiences further. It is also important to note that another method may have had the opposite outcome and result in participants not feeling comfortable to share information or to take part in the study.

Additionally, this, and all research, suffers from sample bias as research requires participants to volunteer to be part of research. This research study is concerned with trans+ people, who have been historically mistreated within research, and a sensitive topic, cervical screening. It is possible that people may have felt uncomfortable being part of this research. For example, trans+ people who do not attend screening may have worried that I would have tried to pressure them into attending screening. Further, discussing cervical screening can be distressing and thus trans+ people who have had particularly negative experiences of screening may have found these experiences too difficult to talk about. Contrastingly, some trans+ people may have had neutral experiences and therefore felt like they had nothing to add. Therefore, experiences such as those which are neutral or are particularly traumatising may have been excluded from this study due to the nature of requiring trans+ people to share their experiences. It is important to note that a strength within this research study was being able to recruit trans+ people and ensure that they felt comfortable to participate in the research, despite the historical mistreatment of trans+ communities.

Finally, an overwhelming majority of research around trans+ people focuses on discrimination, suffering and violence (Westbrook and Shuster, 2023). Although research highlighting these aspects is important to reduce inequality and oppression, sharing stories of trans+ joy is also vital, especially with the recent rise in anti-trans rhetoric, and aids in resisting oppression (Westbrook and Shuster, 2023). Westbrook and Shuster (2023; p16) argue that:

“Narratives of joy reduce stigma, discrimination, and violence by showing how marginalized groups are valid, valuable, and worthy of celebration. Moreover, joy fuels activism against oppression by energizing people and offering alternate possibilities for what life can be like as a member of a marginalized group.”

As seen in the findings, the majority of health experiences within this study are fuelled by discrimination, dysphoria and trauma. Therefore, this study may unintentionally contribute to the dominant narrative of trans+ people having negative experiences associated with their trans identity, whilst ignoring the joys of being transgender.

### 6.3.3 Reflexivity

Reflexivity refers to the practice of a researcher reflecting on how their positionality shapes their research by influencing how they approach the topic, undertake the research, and make sense of the findings (Braun and Clarke, 2022). The inclusion of an in-depth reflexivity section is important within qualitative research and is especially important within this study due to the use of reflexive thematic analysis which requires deep reflection of how the researcher may impact the research. To ensure reflection at each step of the study, I kept a reflexive journal, extracts of which are presented throughout this thesis. A reflexive journal is a vital tool for reflection in which researchers reflect on their own assumptions, research practices, and research design and how these may shape the research, and reflecting on emotions, challenges and dilemmas encountered in the research (Braun and Clarke, 2022). Keeping a reflective journal helped me to reflect on all aspects of the study throughout my PhD. This section provides an in-depth discussion of that reflexivity.

#### The impact of the researchers’ background and personal characteristics in relation to the research topic

One important aspect of reflexivity is considering how my personal characteristics impact the research undertaken. This includes considering my “socio-demographic positioning in relation to intersections of race, culture, religion/belief, social class/socioeconomics, sex/gender, sexuality, ability, age”(Braun and Clarke 2022: p14) and how these inform the research. This involves considering my position in society, such as areas of social privilege and social marginality. Interrogating my positionality is important in research that explores trans+ experiences of health services due to my desire to disrupt cisheteronormativity in healthcare through an intersectional lens, and thus develop recommendations to improve screening in the future.

##### Power and research

In Western societies, in which this research took place, I hold social privilege as a white, non-disabled person, and social marginality as a non-binary, lesbian, working class person. The power and privilege we hold influences how we exist and interact in the social world. There is a wide body of literature discussing the power imbalance between researchers and participants, in which the interviewer has more power than the interviewee (Kvale, 2007). Researchers must consider how this power imbalance impacts research from design to writing the findings. For example, researchers exert power as we create the interview guide and pace of the interview (Kvale, 2007) and decide which elements of research interviews are included within the findings (Ramazanoglu and Holland, 2002). Further, the research interview is usually led by the interviewer as the interviewer asks questions and the interviewee answers, which highlights that researchers hold more power as the interview is not a conversation between equal partners, but a pre-planned method of data collection (Kvale, 2007). This power imbalance may impact how participants respond during interviews, as they may feel compelled to answer questions, and therefore I ensured that participants knew they could refuse to answer any questions and to give as much or as little detail as they preferred in order to share power over the interview with participants. This is also further explored throughout this chapter in relation to recruitment, data collection, data analysis and thesis writing.

##### Insider/outsider positionality

It is also important to reflect on insider/outsider positionality: being an “insider” refers to sharing a characteristic or experience with participants, whereas an “outsider” is not sharing a specific characteristic or experience with participants (Braun and Clarke, 2013). It is impossible to be an “insider” with all participants for all characteristics and experiences (McDonald, 2013), therefore a binary approach in which a researcher positions themselves as an “insider” or “outsider” is not appropriate. For example, all participants were trans+ and therefore I had insider status as a non-binary person. In contrast, I had outsider status to participants who were disabled or not White British.

The impact of insider/outsider status has been widely discussed within literature and has various strengths and limitations. For example, sharing some characteristics provides vital benefits such as access to participant groups, shared understanding, or helping the participants to feel comfortable (Dwyer and Buckle, 2009; Bukamal, 2022). In contrast, being an outsider may lead to difficulties in recruitment, but may also reduce the likeliness of the experiences of the researcher clouding the findings (Dwyer and Buckle, 2009).

Benefits of being an insider when undertaking trans+ research have been discussed both by researchers and their participants. As a result, there is currently a push for trans+ people to be involved at all stages of research, thus borrowing the phrase “nothing about us without us” from the Disability Rights Movement (Scheim *et al.*, 2019; Streed *et al.*, 2023). For example, trans+ participants have reported that when research is trans+ led they experience reduced anxiety and mistrust when considering the intention and potential outcomes of the study, and the researchers underlying knowledge of trans+ issues (Rosenberg and Tilley, 2021). Further, trans+ people are able to talk more openly and freely due to not having to explain terms which cis people may not be aware of (Rosenberg and Tilley, 2021). Finally, trans+ led research is more likely to reflect authentic, nuanced and complex experiences, which can ultimately benefit the community (Scheim *et al.*, 2019; Rosenberg and Tilley, 2021).

All correspondence I had with participants included my pronouns, therefore all participants were aware that I was a non-binary person from first contact. This may have led to an ease in recruitment which may have been more difficult if I was a cis researcher, as my trans+ status highlights to participants that I have an invested personal stake in the research, thus reducing worries about potentially harmful intentions or outcomes. Although I share insider status as a non-binary person, trans+ people are not a homogenous group and thus this insider status is limited. For example, I do not share the same experiences as a trans man or as someone who has medically transitioned. Further, my gender and experiences of gender were more aligned with some participants than others, such as being a non-binary person who is femme presenting, meaning I may have had more “insider” knowledge of some participants’ experiences than others. I also considered the potential weaknesses of insider status throughout the interviews, for example participants knew that I would know what terms such as gender dysphoria felt like and thus did not explain these terms in their own words. Therefore, I made sure I asked participants to expand on their own experiences of gender dysphoria so that I was able to interpret their own experiences in their own words, rather than these interpretations being clouded by my pre-existing knowledge. This ensured that I was able to discuss wide ranges of experiences of gender dysphoria, rather than being told that participants had experienced dysphoria but not understanding what these experiences were like for individual participants. Thus, there are both positives and negatives of sharing an insider/outsider status with participants. This will be further explored throughout this chapter.

#### Reflexivity – recruitment

I considered my own experience as a non-binary researcher when deciding how to approach recruiting participants. For example, a lot of research has been undertaken by researchers who do not have the LGBTQ+ communities’ best interests at heart, and this is even more common for trans+ people. Therefore, many trans+ people, including myself, can be concerned about researchers’ intentions. As a result, I tried to use visual cues within my social media advertisement, for example by using various gender flags such as the non-binary, genderqueer and agender flag, to show that myself, and the research project, are inclusive of all genders rather than only considering transgender men. Further, I offered participants the opportunity to discuss the project with me beforehand. I feel this was especially useful, as many participants asked about my own gender and my reasons for doing the research, which may have been to assess whether I was a person they would feel comfortable discussing experiences with and that I would not use the findings to harm them, whether intentionally or unintentionally due to not having enough knowledge of the trans+ community. Therefore, my insider status as a non-binary person both helped participants to feel more comfortable being part of the research, and shaped the research design as I may not have been aware of elements discussed in this section if I was not part of the community.

In contrast, although I aimed to get a more diverse participant group than previous research on trans+ health experiences, 13/15 participants were White British. During recruitment I asked organisations which trans+ people of colour may engage with to share the call for recruitment, such as Black Beetle Health; an organisation which aims to improve health experiences for LGBTQ+ people of colour, however this was unsuccessful. My outsider status as a white person may have contributed to this lack of diversity.

During recruitment, a small number of members of the public also expressed anger about this project being undertaken at all. For example, one twitter user stated that the project would not be needed if people did not “change their gender”. This rhetoric may have had a negative impact on potential participants who saw negative replies to the calls for participants. I also experienced one trans+ person who was worried that this project would be used to coerce trans+ people into being part of this project. I had an open conversation with this person about the aims of the project, and they decided that they would not be part of it. Therefore, I spent some time reflecting on how calls for participants may impact trans+ people and potential ways to do this differently in the future. For example, it may be worth turning off replies to recruitment posts to avoid negative responses from the wider public in order to minimise harm to trans+ people who see the post, however this would also restrict potential participants ability to ask questions relating to the project, or for it to be shared more widely. Further, it may be useful to be more explicit about exactly how the data will be used within recruitment posts to avoid creating upset to trans+ people, who have already been mistreated within research.

#### Reflexivity – data collection

The data collection methods were shaped by my positionality, including my beliefs about the world, knowledge and the most appropriate ways to elicit data from trans+ participants. I used a qualitative methodology, semi-structured interviews and asynchronous online focus groups because I believe it is imperative to allow trans+ people to share their experiences in their own words and in a way in which they feel comfortable.

Initially, I was nervous when undertaking interviews however I became more confident with practice and reflection on previous interviews, such as within the reflexive diary extract on page 61. For example, I became more comfortable with eliciting experiences from participants who were introverted or reluctant to share freely. I aimed to make the interviews as informal as possible by allowing participants to drift away from the interview guide and speak freely in their own way. Multiple participants shared that they felt comfortable discussing their experiences of screening with me, including stating that they shared things with me that they would not feel comfortable sharing with health professionals.

My use of a semi-structured interview, in which I followed an interview guide as a way to keep the interview on track, but also allowed and encouraged participants to speak freely and in whichever way they felt most comfortable, may have lessened the power imbalance during the interview. I also gave participants the opportunity to ask questions before, during and after interviews, and shared my own experiences which may have made the interview feel more conversational and less formal. My age may also have contributed to lessening the power imbalance between myself and participants, as I was under the age which cervical screening begins, and thus was younger than all participants. Some participants asked about my experiences of screening, to which I replied that I had not been due to my age. This led to a number of participants trying to encourage me to go by saying it is not always that bad, or even saying they are old enough to be my parent. These conversations usually happened towards the end of the interview, when discussing potential improvements, and therefore the impact may be minimal however, being aware that I had not attended cervical screening may have impacted the interview as participants may have been more open with someone who had been so that they did not scare me out of attending. Therefore, although I believe it is impossible to remove the power imbalance between researchers and participants, there are some factors such as my age and decisions about the method which may have mitigated the impact of power within this research.

Further, the use of an asynchronous online focus group allowed participants who were not comfortable discussing their experiences in an interview setting to be part of the research, whilst keeping the rich detail that is lost when undertaking methods such as questionnaires. Participants shared highly detailed answers to prompts, however there was less discussion between participants than I had anticipated. Upon reflection of my own asynchronous focus group, and my experiences of being an asynchronous focus group participant in a project following the end of my data collection, I believe that focus groups are an excellent form of data collection with underserved participants and/or vulnerable topics, however I may make changes to its undertaking in the future. For example, the group I participated in used Google groups which I believe may work better, as well as encouraging participants to write one post and reply to three other comments every day in order to see discussion. Implementing these changes may have generated more detailed data, and thus I encourage their use in future focus groups.

#### Reflexivity – data analysis and thesis writing

Research findings do not naturally emerge from data, instead they are shaped by choices made by the researcher and the experiences shared by participants (Davis, 2020). Discussing reflexivity in relation to data analysis makes the research process and decisions more transparent and rigorous (Davis, 2020) and is a vital aspect of undertaking reflexive thematic analysis (Braun and Clarke, 2022).

This thesis presents a co-construction of knowledge through participants interpretations of their experiences, and my interpretations of how this was shared with me. Therefore, when undertaking analysis, I was mindful of my insider status as a non-binary person and took care to make sure that my own experiences were not clouding my interpretations of participants experiences. Further, I considered the power imbalance as I, the researcher, have the final say in what is included within the research findings, and thus aimed to ensure that the findings did justice to the rich, complex and nuanced experiences that participants shared with me. For example, as demonstrated in the reflexive diary extract below, I ensured that although the findings were interpreted and influenced by me, these interpretations were firmly grounded in the participants words and meanings they placed on their experiences.

|  |  |
| --- | --- |
| Reflexive diary extract: 06/07/23  Analysis and thinking about writing up | I’m really sitting with each line/section/sentence to see what the participant was trying to get across and uncover what they meant and what is important to them, trying to find a balance between interpretation and making sure I’m not attaching stuff to the conversation that they didn’t really mean. It’s interesting to see how the start of my finding fits in and adds to current literature. |

## 6.4 Summary of the discussion chapter

To summarise, this chapter situates the thesis findings within the wider literature in areas related to trans+ health or cervical screening to provide a critical discussion of the findings in this thesis. Section one discussed the complexities and nuance of transmasculine peoples’ experiences of cervical screening to provide a more in-depth understanding of factors which influence both trans+ peoples decisions to attend screening, and their experiences of attending screening, than was previously available. Section two explored the two key contributions to knowledge which lie in the novel approach to, and the importance of intersectionality and diversity within, trans+ health research. Finally, section three assessed the quality of this thesis by exploring the various strengths and limitations of the research undertaken and discussing reflexivity in-depth. By discussing the reflexive elements of the research process for my PhD, this has enabled me to show transparency throughout the study, including its conception, design, data collection, analysis and thesis writing. This is important as it demonstrates how the research findings were co-constructed between myself and participants. Therefore, within this chapter, the thesis aims have been achieved and the research questions outlined in chapter two have been answered. The following chapter provides a more in-depth answer to the final two research questions:

* What improvements, modifications or changes do TMNB think are most important to improve these experiences?
* What are the implications of this for future policy development and changes to health care practice within the NHS?

# Chapter Seven – Implications for policy, practice and future research

This chapter provides a discussion of the implications of the research findings for policy, practice and future research. This includes the importance of improving education about trans+ identities and trans+ health, implementing person centred care, and offering small modifications to the cervical screening procedure. Further, I highlight the need for trans-inclusive health policy, and for further research which considers the experiences of trans+ people with multiple marginalised characteristics.

## 7.1 Implications for practice

In this section, I address the final research question: “What are the implications of this project for future policy development and changes to health care practice within the NHS?”. This PhD study created many implications which may improve cervical screening experiences for trans+ people, and which may be applied to wider health services. For example, this thesis includes a discussion of a myriad of potential ways to improve cervical screening for trans+ people, as presented in theme four. These include giving patients more choice and autonomy, improving trauma informed care, de-gendering cervical screening, and providing modifications to the procedure such as allowing participants to use a smaller speculum or insert the speculum themselves. This section discusses how these recommendations may be implemented into medical curricula and health practice.

### 7.1.1 – Improving health professionals’ education on trans+ health

The findings from this thesis highlight that health professionals’ lack of education on trans+ health affects trans+ patients’ experiences of cervical screening as well as wider health services. Previous research both with patients and providers has documented that health professionals limited education on trans+ health is widespread across healthcare, for example among GPs and practice nurses (Mikulak *et al.*, 2021), mental health services (Boutilier *et al.*, 2024) and obstetrics/gynaecology (Unger, 2015). This limited training on trans+ identities and specific health needs has also been reported across various countries such as the UK (Mikulak *et al.*, 2021; Canvin, Twist and Solomons, 2023), USA (Unger, 2015; Shires *et al.*, 2019b), and Georgia, Poland, Serbia, Spain and Sweden (Burgwal *et al.*, 2021). For example, a qualitative study involving 20 GPs and practice nurses found that trans+ health was not sufficiently covered during medical/nursing school, including having little to no mention of trans+ people throughout their time in education (Mikulak *et al.*, 2021). Research has also highlighted that health professionals who feel they lack knowledge on caring for trans+ patients can feel uncomfortable when providing care (Safer and Pearce, 2013). Healthcare providers report wanting to provide appropriate care for trans+ people but a lack of education on trans+ health hinders their ability (Canvin, Twist and Solomons, 2023). For example, providers report feeling worried about offending or causing emotional harm to trans+ people unintentionally due to not having adequate training (Canvin, Twist and Solomons, 2023). Similar to the findings from this thesis, previous research, for example Boutilier et al. (2024), has also found that a lack of education on trans+ identities or specific health needs creates hesitancy among trans+ people accessing health care due to concerns about how they will be treated by health professionals. Therefore, improving education and training about trans+ health among health professionals may improve trans+ peoples’ feelings of trust and safety within the NHS due to the improved understandings of trans+ health. This may help trans+ people to feel more comfortable when accessing cervical screening and wider health services. Further, improving education should help providers to build confidence and competence when caring for trans+ people (Burgwal *et al.*, 2021; Canvin, Twist and Solomons, 2023).

Within this study, participants suggested various aspects of trans+ lives and trans+ health that they believe health professionals should be aware of. This includes the following, however this is not derivative of all information health professionals should be given about providing care for trans+ people:

* Health professionals should be LGBTQ+ inclusive as a whole during any health service, and not make assumptions about people’s sexualities or gender. For example, they should be aware that being sexually active does not necessarily mean there is a risk of pregnancy.
* Training should ensure that health professionals are aware of what it means to be trans+, including trans men, trans women, and non-binary genders. This should include that transition looks different to different trans+ people, i.e. that not all trans people will want (or be able to access) gender affirming hormones or surgeries.
* Health professionals should be made aware of the impact of hormone therapy on their bodies; for example, being aware of lower growth from testosterone. This may help to reduce anxiety about how bodies will be judged.
* Appropriate terminology and behaviours to use towards trans people should be explored within training: i.e. ensuring the correct name and pronouns are used, not asking inappropriate questions about their gender, and not making comments on patients’ bodies.
* Health professionals should be aware of issues which may arise from gender affirming hormone use in relation to cervical cancer screening, i.e. that transmasculine people using testosterone may find cervical screening more painful due to the drying and thinning of genitals.
* Finally, training should inform health professionals of ways in which to comfort, reassure and affirm their trans+ participants, such as reminding them that screening is a good thing to do to look after their bodies, rather than something specifically for women.

The findings also suggest that the onus on educating health professionals about trans+ health is often placed upon trans+ patients themselves. Participants felt frustrated about this, but willing to share information with health professionals in order to benefit future trans+ patients by improving health professionals’ knowledge. For example, this would allow future trans+ patients to not have to explain what being non-binary is, which participants often found frustrating. Previous literature has also discussed that trans+ people feel as if they are treated as a learning opportunity for health professionals, and experience frustration that they are frequently asked to educate health professionals due to the lack of formalised education and training (Kermode, 2019). Therefore, medical education and training should be improved to ensure that, at a minimum, no trans+ person is met with a medical professional who doesn’t know what the terms transgender or non-binary mean, without placing this on trans+ people themselves. Further, health professionals should be taught LGBTQ+ health more widely. Although developing recommendations for this is beyond the scope of this study, one important implication is improving understandings of asexuality among health professionals to prevent inappropriate comments or assumptions from being made, such as those experienced by Toothless. Health professionals should also be encouraged to engage in reflection on their own unconscious biases towards trans+ people, as health professionals harbouring negative beliefs towards trans+ people was also a significant worry among trans+ participants in this PhD study.

Participants in this PhD study also stressed the importance of health professionals understanding the impact of trauma and the diversity of peoples experiences and identities. Potter et al. (2015) emphasised the need for health professionals, specifically nurses, to be trauma informed and understand how different lived and healthcare experiences may impact health care access. Improving trauma informed care among health professionals is vital in improving health experiences for people who have experienced trauma, especially when considering health services which may be triggering such as cervical screening.

Therefore, the above list could therefore be used as a basis to embed into medical or nursing school curricula, or to create training sessions for health professionals about trans+ health, which can be expanded to be more specific for different specialisms.

### 7.1.2 – What works for who? Implementing person-centred care

This thesis highlighted that trans+ participants often feel worried about physical and emotional aspects of the screening procedure, such as physical pain or discomfort, gender dysphoria and the impact of sexual trauma. These could be alleviated by implementing the principles of person-centred care. This involves tailoring health services to the needs of the individual to ensure that patients are always treated with dignity, compassion, and respect and are able to make informed decisions about their own health and health care through collaboration between the patient and health professional about the best course of action (The Health Foundation, 2016). In practice, this would mean that cervical screening appointments would look different depending on the needs, circumstances and preferences of the person receiving the health service, as what is important and helpful to one person may be undesirable to another (The Health Foundation, 2016). For example, many participants shared that using a smaller speculum helped to reduce discomfort and pain but this is not common practice across the North of England. Therefore, health professionals could be made aware that they can offer patients a smaller speculum and this could become consistent practise. Further, increasing the awareness of smaller speculums is important so that trans+ patients can request this themselves in cases where health professionals fail to offer this as an option. It would also be useful for patients to be involved in a discussion about which speculum they found easier, more comfortable and less painful so that they are able to request this type of speculum in the future. This would give trans+ patients more choice about what happens to their body during screening procedures, and may also be useful for cisgender women who experience discomfort or anxiety around cervical screening. How this may be navigated with regards to time constraints is discussed later within this chapter.

Person centred care requires health professionals to ‘empower’ patients by giving them the confidence, voice and power to advocate for their own needs, and sharing the decision making in order to create an approach to the health service which works for the patient (The Health Foundation, 2016; Skills for Care, 2017). Whilst most published literature focuses on the advantages of person centred-care, which may be due to researchers who publish in this field having a positive attitude towards person centred-care, there are also criticisms (Meranius *et al.*, 2020). Firstly, some researchers argue that person centred care has become a “buzzword” which has lost meaning due to it being open to different interpretations and definitions (Tieu *et al.*, 2022). This complicates the implementation of a consistent approach to person centred care.

Secondly, person centred care may exclude certain groups because it assumes that patients are both able to, and want to, make decisions about their care, and that everyone is able to make rational and informed decisions (Tieu *et al.*, 2022). The requirement for patients to make informed decisions and be active participants in their healthcare may disadvantage patients who are less confident or have “weaker” voices, who may not want to be involved in their care, or who may be unable to make decisions about their own care (Meranius *et al.*, 2020; Tieu *et al.*, 2022). Further, healthcare staff may treat patients differently which results in unfair care, for example by favouring and providing better healthcare to patients who are verbal and articulate and who may be able to develop a better rapport with health professionals, whilst unfairly disadvantaging patients who may find communication or trust difficult (Meranius *et al.*, 2020).

There are also criticisms of the philosophical and humanistic underpinnings associated with person centred care, as contextualised within Black, queer feminism and critical disability studies (Smith, Willis and Hopkins-Walsh, 2022). Person centred care was developed in response to the historical dehumanisation of people who require care. For example, healthcare often ignores groups of people based on racism, ageism, transphobia, homophobia and ableism, such as people with learning disabilities being excluded widely within health research which means that evidence based practice does not consider their experiences (Smith, Willis and Hopkins-Walsh, 2022). However, person centred care has been criticised as it does not address the power disparities within healthcare systems or the diverse experiences of all people, and thus does not address equity for all people and communities (Smith, Willis and Hopkins-Walsh, 2022).

Finally, implementing person centred care is an additional engagement for healthcare staff, who are often already overloaded (Meranius *et al.*, 2020). The increased workload for healthcare staff creates a risk of compassion fatigue, which refers to feelings of hopelessness, anxiety, stress, exhaustion and lessened compassion (Meranius *et al.*, 2020), which would impact patient care. Further, interactions with patients are often time constrained which may hinder the ability to deliver person centred care appropriately (Moore *et al.*, 2017). Adopting person centred approaches is also time consuming, for example it requires healthcare workers to engage with training and for policy to be developed (Moore *et al.*, 2017). However, once embedded, person centred care has been shown to save time due to patients taking responsibility for their own care and patients goals being effectively discussed and supported (Moore *et al.*, 2017). Therefore, despite these disadvantages, there are many positive aspects of person-centred care which have been shown to improve patient experience.

One way to implement person centred care would be to improve cervical screening consultations, which may help to remove discomfort and empower participants to choose what will make them feel most comfortable. This thesis highlights the importance of health professionals’ behaviours on creating a positive or neutral health service experience. As discussed in Theme Four, participants felt more comfortable and cared for when HCPs asked if they had been screened before, what this experience was like, and if there was anything that could have helped. A key element of theme four was also giving patients as much choice as possible with regards to their screening appointment. Having an open discussion about these elements prior to starting the procedure may help patients to feel more comfortable. Therefore, creating a checklist of what to ask patients before the screening procedure begins may be useful in improving experiences. This may include, but is not limited to, the following:

1. Have you been to cervical screening before?
2. What are your previous experiences of cervical cancer screening or other vaginal examinations?
3. Would you like me to talk you through the procedure?
4. Would you like me to ask before continuing at each step of the process?
5. Is there anything you found useful in previous appointments, or anything that you would like to avoid?
6. Finally, it may be useful to share information about modifications to the procedure which may ease physical or emotional discomfort, such as offering the use of a smaller speculum, self-insertion, or placing a pillow under their hips. This could also include sharing trans+ specific information, such as the potential for testosterone to make screening more uncomfortable.

A conversation using the above guide brings together the health care professionals expertise on appropriate options, risks and benefits, whilst also considering the patients’ preferences, personal and social circumstances (The Health Foundation, 2016). This therefore allows the collaborative development a strategy between patient and health professional to approach cervical screening which helps the patient to feel as comfortable as possible. Where possible, it may be useful to have these conversations prior to the screening appointment, for example if a patient shares their concern about attending screening in the future, both to reduce anxiety in the time leading up to the appointment, as well as to give patients more choices about their appointment such as deciding to bring a trusted person or booking a double appointment. This should be offered in any conversations with patients about overdue cervical screening appointments. It is recommended that health professionals respond appropriately to anything that patients may disclose, for example if a patient discloses that they have struggled with screening previously, health professionals should be reassuring and should consider how they can ease this discomfort. Unfortunately, within this thesis, it was identified that participants expressions of discomfort were sometimes ignored or belittled by health professionals, and modifications which trans+ people had found useful previously were ignored in future appointments. For example, Blue told a health professional that having a pillow under their hips helped to ease the pain and discomfort from screening previously, however the health professional acknowledged but ignored this and Blue felt increased pain. This should be avoided, and instead patients wishes should be considered to ensure limited discomfort, and to reduce the likeliness of the procedure being abandoned.

Person centred care also places importance on emotional and mental wellbeing, including minimising factors which might cause patients discomfort or distress, such as lighting or noise (Skills for Care, 2017). Ensuring these factors are considered may be helpful for trans+ patients with disabilities, as the findings highlight that disabled trans+ patients, especially those who are neurodivergent, may feel uncomfortable attending medical settings due to the bright lighting and loud noises, which may be a barrier to accessing screening. Therefore, asking patients about their needs and responding to these however possible may help patients to feel more comfortable and cared about during screening.

Due to the challenges the NHS is currently facing, such as long waiting times, this may seem like a low priority, however ensuring quality of care is vital to ensure that patients are treated with dignity, respect and compassion (The Health Foundation, 2016). Further, patients often only get a small amount of time within appointments so these discussions may not be viable, however in cases where patients book a double appointment, practitioners should aim to discuss some of the elements discussed above. There is also evidence that person centred care may have financial benefits by saving money in the long run (The Health Foundation, 2016). For example, if cervical screening appointments are tailored to make patients feel more comfortable, they may be more likely to obtain an adequate sample, meaning they won’t have to book a second appointment to retry.

### 7.1.3 The use of small changes to the procedure and coping strategies

This thesis provides a number of recommendations for improving cervical screening experiences for trans+ people, as presented in theme four. As explored throughout this thesis, trans+ experiences of cervical screening are complex and involve the interaction of multiple factors, and therefore improving screening experiences is similarly complex and requires the implementation of multiple improvements. Therefore, offering some of the following accommodations to trans+ people cannot be expected to improve experiences for all trans+ people, but may be vital for others.

Firstly, smaller speculums should be offered to reduce pain. As above, it is clear from the findings that this is offered to some patients and not others, however a smaller speculum was associated with reduced pain. Additionally, participants in this PhD study often made reference to the speculum when discussing concerns about cervical screening. It seems that the speculum was a great source of anxiety, as well as physical pain. Previous research has found that the speculum was the most off-putting part of cervical screening for trans+ people (Berner, Suchak, *et al.*, 2021). Therefore, offering a smaller speculum should become standard practice for people who experience pain or feel anxiety about the speculum.

Secondly, offering self-insertion of the speculum may improve screening experiences for trans+ people. Within this study, one participant had been offered self-insertion but did not feel comfortable doing that at the time. As discussed in theme four, participants had varying opinions about whether they would accept self-insertion, but agreed that this should be offered for those who would benefit. Self-insertion has been offered previously but is not widespread, for example one trans+ participant in a UK based research study was offered to take the speculum home to practice inserting the speculum in a more comfortable setting (Berner, Connolly, *et al.*, 2021). This, along with the findings presented in theme four, suggests that self-insertion may improve trans+ peoples experiences of cervical screening. Therefore, further research should be undertaken to explore whether offering self-insertion of the speculum would be an appropriate modification to cervical screening, for example by considering whether this would have any effect on the adequacy of the sample.

Finally, some participants within this thesis also shared that they felt more comfortable bringing a trusted friend to their cervical screening appointment who was able to advocate for them or act as a distraction. This highlights that taking a trusted person may alleviate trans+ people’s concerns and discomfort about attending cervical screening. However, not all participants were aware that this was an option. For example, one participant stated that they had been offered a “chaperone” but felt that if they had known this could be a person they brought themselves they may have used this. Therefore, bringing a trusted person should be offered to trans+ people attending cervical screening, and potentially other people who may benefit, and it should be made clear that this can be a person of their choosing. Further, one participant disclosed their concerns that the person they chose would not be treated appropriately, and therefore health professionals should ensure that both patient and anyone accompanying them should be treated in a respectful manner during appointments.

Additionally, neurodivergent people may have different needs to neurotypical people whilst attending screening and thus may benefit from additional coping strategies. Autistic participants within this thesis shared a number of coping strategies for cervical screening. For example, participants shared that taking fidget toys or wearing headphones to cervical screening provides support for their sensory needs, for example by reducing overstimulation. However, participants also shared difficulties relating to sensory needs when attending health settings, for example feeling unable to wear headphones due to worries about not hearing healthcare staff call their name. Considering sensory needs such as taking sensory aids, such as fidget toys or headphones, may help neurodivergent people to feel more comfortable at screening (Khan and Richardson, 2022). Furthermore, Khan and Richardson, (2022) suggest that autistic people should consider their communication needs, such as by bringing a trusted person to support verbal communication.

Finally, whilst waiting for changes in policy and practice, I argue that it is important to increase awareness of available modifications. As above, modifications such as the use of a smaller speculum or inserting the speculum themselves have been offered by some health professionals, but evidently this is not widespread across health staff. Therefore, raising awareness of what accommodations trans+ people are able to ask for may help to improve experiences in areas where health professionals may be unaware of or unwilling to provide options for trans+ people. Although this places the onus onto trans+ people themselves, some trans+ people may benefit. Further, empowering trans+ people with knowledge, such as the requirement for health professionals to stop when asked, may help them to feel more able to demand the immediate cessation of the cervical screening procedure when required to avoid distress or trauma from such experiences. Hopefully, equipping trans+ people themselves with this knowledge may ensure that within most cervical screening appointments, the health professional either offers, or the patient requests, any changes which may help to ease discomfort during the procedure.

## 7.2 – Implications for policy

The findings from this thesis can inform policy development regarding providing cervical screening for trans+ people, and for wider trans+ health. A key finding is the need for health professionals to be educated on trans+ identities and specific health needs and trauma informed care when providing health services which may be invasive or triggering. Improving trans+ peoples experiences of healthcare requires trans+ people to be reflected in policy. For example, ensuring that health professionals undertake training which demonstrates how to care for trans+ people is vital to reduce negative experiences within healthcare. Participants within this thesis shared that a large source of anxiety about attending screening was concerns about how they would be treated by health professionals, thus developing policy, including requirements to attend training, on how to treat trans+ people may reduce this anxiety. This may include more general policy, such as requiring the use of patients chosen name and pronouns, even when this is different to those written on records, and developing specialism-specific policy which addresses trans+ health, which may help to improve trans+ peoples experiences of that health service, and willingness to reattend. This must be implemented widely and not just with patient facing staff. For example, labs have refused to process samples taking during cervical screening when the name on the sample is male, and thus ensuring that staff working in labs are aware that trans+ people may access screening can reduce the likelihood of this occurring. Further, removing systemic barriers, such as trans+ people not being included in automatic screening invitations may help trans+ people to feel included and considered within health care.

This thesis also highlighted trans+ people’s desire for visible indicators of being trans+ friendly, such as wearing pronoun pins or displaying inclusive policy or training to show that the practice is knowledgeable of trans health. Further, GP and practice nurses in the UK reported that the lack of policy and guidelines for supporting trans+ people was a key issue in providing appropriate care to trans+ patients (Mikulak *et al.*, 2021). This study also found that health professionals were often unaware of what terms such as “non-binary” meant, which participants found distressing as they had to explain and validify their identity. Additionally, previous research has found that non-binary people feel they are treated as binary genders, such as being seen as trans men or trans women, rather than non-binary, leading to them feeling misunderstood and like their care was not sensitive to their gender identity (Lykens, Leblanc and Bockting, 2018). For example, non-binary people have reported being treated as a binary gender if they have a condition usually associated with a specific gender, such as a non-binary person with endometriosis being viewed as a woman rather than a non-binary person (Eiduson *et al.*, 2021). Therefore, policy should be developed and implemented to ensure that healthcare staff are aware of trans identities and providing appropriate care for trans+ people. It may also be appropriate to create specific policy or guidelines for non-binary people to ensure that their care considers any non-binary specific needs, rather than being treated as a binary gender. Displaying this in practice may help trans+ patients to feel comfortable in the knowledge that trans+ people have been considered by the staff there. Further, providing knowledge to staff may help them to feel more confident and competent when caring for trans+ patients.

## 7.3 Implications for future research

This thesis has highlighted the importance of taking an intersectional approach to trans+ health research. A key implication for future research is making sure any research considers how trans+ people with multiple marginalised characteristics may experience health services differently. This thesis also highlights the need for further research on cervical screening to be undertaken considering different groups, their experiences and how these may be improved. For example, cervical screening research which considers the experiences of trans+ people who are aged over 45, people of colour, people with disabilities such as energy limiting conditions, and those who have experienced sexual trauma. Each of these elements of experience or identity may have specific impacts on access and experience of cervical screening, and thus require specific policy and practice change to improve experience for those people. For example, although it was not addressed within this study, socioeconomic status also impacts cervical cancer screening uptake in the UK (Douglas *et al.*, 2016). Trans+ people are more likely to be of a lower class and lower socioeconomic status (Faye, 2022) and therefore future research should take care to understand how this impacts trans+ peoples experiences of screening. This research should also be undertaken intersectionally, for example disabled people are also more likely to be in poverty and thus trans+ disabled people with a lower socioeconomic background due to having to tackle issues related to their trans+ identity, disability, and socioeconomic background, and thus may have different experiences to non-disabled trans+ people (Lamba *et al.*, 2023).

A second implication for future research is the importance of undertaking further qualitative research. As discussed in Chapter Three: Methodology, qualitative research is vital to understanding health care experiences, and therefore qualitative understandings of trans+ peoples reasons for finding cervical screening difficult may help to develop potential improvements with the service. Further, as shown within this thesis, giving trans+ people the space to talk freely about their experience of screening may allow suggestions for improving screening to be expressed by trans+ participants themselves, such as implementing key characteristics from positive experiences shared by participants. It is vital to ensure that trans+ participants are recruited as widely as possible, for example by ensuring that recruitment isn’t only undertaken through trans-specific clinics or trans organisations which is a key limitation of much of the currently published literature.

Finally, future research should consider the impact of the rise in anti-trans rhetoric within the media and legislation in the UK and across the world. Although some participants within this study referenced the impact of the rising anti-trans rhetoric on their health experiences, data was collected between November 2022-March 2023, and the impact of consistently seeing negativity and hatred surrounding trans+ people in the media may have further impacted participants. For example, Robin stated that they did not believe that health services would ever be good for trans+ people, however this view may have been amplified by consistently seeing attacks on trans+ people, trans+ rights and trans+ health over almost two years since the interview. It is clear that these movements are negatively impacting trans+ peoples mental health and everyday life, as well as hindering the progress and significant achievements in improving discrimination and reducing violence towards trans+ people (Madrigal-Borloz, 2023). However, since undertaking data collection and whilst writing this thesis, there have been further steps back regarding trans+ rights and an increase of anti-trans media and legislation in the UK, such as efforts to censor school curriculums discussion of trans+ people and to ban gender affirming care such as puberty blockers for trans+ youth. The impact of this on trans+ peoples mental health and health experiences must not be dismissed when undertaking research, and when considering how trans+ peoples perceptions and experiences may change over time. Therefore, future research should endeavour to explore the impact of this on trans+ peoples’ experiences of health services.

## Summary of implications

To summarise, this section provides implications for practice, policy and future research. This includes ensuring that health professionals are given appropriate training and education about providing care for trans+ patients and about trauma informed care. It also discusses the importance of person-centred care in improving experiences of screening for trans+ people, and for other groups who may find screening distressing and thus may find comfort in making choices about what is appropriate for them. The need for trans+ inclusive policy within health services is then outlined, followed by recommendations for future research within the area of cervical screening for trans+ people.

# Thesis Conclusion

This thesis has explored trans+ peoples experiences of accessing and attending cervical screening in the north of England. The qualitative method, developed with a desire for inclusivity and sensitivity due to the nature of the topic area, allowed for the co-construction of findings through participants experiences and my interpretations. This means that the findings centre the participants experiences of cervical screening and reflect what trans+ people themselves feel is important for research to include and for health professionals to be aware of.

The research questions developed from the scoping review have been sufficiently answered throughout this thesis. Questions one and two focus on learning about trans+ experiences of screening to understand how positive or negative experiences are created, and to learn from these experiences how to better understand and support screening in the future. Question three required a discussion of improvements and changes which trans+ people feel are important to improve their experiences of cervical screening, which is presented within Theme Four of the findings, the discussion and implications chapters. Finally, question four, which addresses the implications of participants experiences for future policy and changes to healthcare practice within the NHS is answered in Chapter 7: Implications for policy, practice and research.

The research findings highlight the complexities of cervical screening for trans+ people, including decisions to access screening and experiences of the service. Multiple barriers to accessing screening were identified, including gender dysphoria, a history of sexual trauma and distrust in the health system and/or health professionals. Facilitators to cervical screening include having a knowledgeable and compassionate health professional, feeling affirmed outside of cervical screening, and making small changes to the procedure which can result in a reduction in physical and/or emotional discomfort. As there is a paucity of qualitative research in this area, this thesis has provided a more in-depth understanding of the reasons that trans+ people may decide whether to attend screening, and the multiple factors which interact to influence their experiences of cervical screening. Further, it allowed trans+ people themselves to share what is important to them with regards to improving access to cervical screening, including sharing things that they may find vital, useful or not useful in improving their experiences. It also highlights the importance that trans+ people place on the wider trans+ community, as multiple participants referenced the importance of discussing cervical screening with trans+ friends, or discussed potential improvements which they themselves would not find useful but that other trans+ people may, and were willing to push for these to be brough into practice.

Key contributions to knowledge identified within this thesis were the importance of intersectionality to understand how having multiple marginalised identities may impact trans+ health experiences, and using inclusive and accessible research methods to ensure that trans+ people can engage with research in a way in which they feel comfortable. However, gaps in understandings of trans+ experiences of cervical screening remain. For example, this thesis is unable to address the experiences of screening among trans+ people of colour, trans+ migrants, or how different socioeconomic statuses impact experiences of cervical screening. Research which focuses on each of these elements would help to build a deeper understanding of trans+ health experiences and thus allow the development of improvements which address the needs of groups which are not represented within this study.

This thesis highlights the need for primary care to change its approach to providing cervical screening for trans+ people, and to consider how people living with different intersections may have different needs. Trans+ people deserve to feel safe and supported within health services. This requires improving understanding of trans+ experiences of health services and responding to these in a sensitive, open and non-judgemental manner. The findings from this thesis can be applied to other areas of healthcare for trans+ people. For example, health professionals should approach trans+ patients in an inclusive, sensitive and open manner which involves considering how health needs may be different. Further, improving education about caring for trans+ people in specific health services, including but not limited to cervical screening, may help to improve trust among trans+ people in being provided appropriate care. Findings such as improving trauma informed care and person-centred care can also be applied to other groups to ensure that all people are able to undergo cervical screening in a way in which they feel most comfortable. The findings of this thesis are relevant to researchers, policymakers and practitioners who are invested in improving equality and health experiences for trans+ populations.

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# Appendices

## Appendix 1 – Journal Article of Scoping review

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**S C O P I N G R E V I E W**

**Transgender and non- binary peoples experiences of cervical cancer screening: A scoping review**

**Georgia Rivers PhD Student,** | **Sharron Hinchliff PhD, Professor**| **Jill Thompson PhD, Senior Lecturer**

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| --- | --- | --- |
|  | |  | | --- | | **Abstract**  **Aim(s):** To synthesise the literature about transgender and non- binary people's experiences of cervical cancer screening and identify ways to improve screening.  **Background:** Transgender people often face barriers to accessing health services including cervical screening, where transgender people have a lower uptake than cisgender women.  **Design:** A scoping review was undertaken following the Arksey and O’Malley (2005) framework and the PRISMA- ScR checklist. Following database searching of Medline via PubMed, Web of Science, Scopus and CINHAL, 23 papers published between 2008 and 2023 were included. Papers were included if they shared trans and non- binary people's experiences of cervical screening and were written in English. There were no date or geographical data restrictions due to the paucity of research.  **Results:** Transgender people experience barriers to cervical screening including gender dysphoria, a history of sexual trauma, and mistrust in health professionals or health services, which can result in having negative experiences of screening or avoiding screening. Health professionals can help to create a positive experience by informing themselves about best practices for trans+ health.  **Conclusion:** Changes are required to improve transgender people's experiences and uptake of cervical screening. Improving medical education about trans health and updating health systems would help to combat issues discussed.  **Implications for the Profession and/or Patient Care:** Having an understanding of the reasons why accessing health services can be more difficult for transgender people will help health professionals to provide appropriate care for transgender patients. This paper details this in the context of cervical cancer screening and can be applied to other areas of healthcare.  **Reporting Method:** We have adhered to relevant EQUATOR guidelines and used the PRISMA- ScR reporting method. No Patient or Public Contribution.  **KEYWORDS**  cultural competency, gender, health screening, LGBTQI, patients' experience, scoping review, screening, sexual health | |

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|**INTRODUCTION**

Inequality and discrimination of transgender people is evident in all areas of life, including medicine and healthcare (Faye, 2022). The term transgender refers to people who identify as a gender other than their sex assigned at birth, whereas, a cisgender person is someone who identifies with their sex assigned at birth (Stonewall, 2017).[[5]](#footnote-5) This scoping review synthesises published research in this area to show what is currently known about trans men and non- binary peoples (TMNB) experiences of cervical cancer screening (CCS).

Globally, trans people have low rates of access to healthcare due to issues such as violence, legal barriers and discrimination. For example, most countries do not legally recognise transgender identities, which contributes to exclusion and marginalisation (World Health Organisation, 2022). The Equality Act 2010 states the legal duty of all health and social care organisations in the UK to provide equal treatment; however, trans people often face adversity within these services (Bachmann & Gooch, 2018). The LGBT in Britain Health Report (Bachmann & Gooch, 2018) drawing on a survey of 5375 LGBT people, including 752 trans people, found that 32% of trans people had experienced unequal treatment within the National Health Service (NHS), including inappropriate curiosity and discriminatory remarks from healthcare staff. These experiences can lead to trans people mistrusting health professionals or avoiding healthcare due to experienced or expected discrimination (Bachmann & Gooch, 2018; Pearce, 2018). Additionally, 62% of trans people reported NHS staff lacked understanding about trans- specific health needs (Bachmann & Gooch, 2018). This may be due to the lack of education on trans healthcare, which is seen as a specialty area only necessary for those who will work in gender affirming care, even though trans people have the right to good healthcare in all areas (Vincent, 2018).

Furthermore, 40% of trans people said they had experienced difficulties accessing healthcare due to their trans status (Bachmann & Gooch, 2018). For example, a high proportion of TMNB report gender- identity discrimination in healthcare, which can deter them from seeking healthcare in the future (Eiduson et al., 2021). TMNB who have had negative experiences with healthcare professionals (HCP), or heard of such stories from others, can anticipate further mistreatment, which can lead to delaying treatment (Gomez et al., 2021).

Gendered health settings can also cause discomfort among TMNB, for example the gendered language within health services may feel like a constant stressor, leading to heightened dysphoria (Gomez et al., 2021). Many healthcare settings and providers intentionally or unintentionally treat TMNB as abnormal or ‘other’ due to

**What does this paper contribute to the wider global community?**

* This paper provides insight into transgender and non- binary peoples' experiences of cervical screening, including factors that lead to a lower uptake of screening in this group.
* The implications will be useful for service providers and health professionals who deliver cervical screening, helping to increase uptake and make screening less daunting for trans+ people.

the extent of cisnormativity in healthcare. This means TMNB must constantly combat assumptions about their bodies, their gender and their sexuality, which can decrease willingness to return for necessary healthcare (Eiduson et al., 2021). Furthermore, non- binary individuals are often treated as a binary gender, especially in situations or conditions that are usually associated with a specific gender. For example, in a recent study, a non- binary participant with endometriosis was perceived as a woman, that is in language used in relation to the condition (Eiduson et al., 2021). This highlights the need to consider how health services can be supported to be more inclusive and meet the needs of binary and non- binary trans people.

A health service where this is particularly apparent is CCS as trans people are less likely to attend this service than their cisgender counterparts. A small number of United States (US)/ Canada research has aimed to quantify this, for example a Canadian study reported that trans+ people are 60% less likely to attend this service (Kiran, 2019). Cervical cancer symptoms include unusual vaginal bleeding or discharge, pain during sex and pelvic pain; however, many people with cervical cancer do not experience symptoms (Cancer Research UK, 2020). Not attending CCS places people at risk of missing early cervical cell changes, meaning the limited uptake of screening among TMNB places them at a higher risk of developing cervical cancer (Dhillon et al., 2020; Reisner et al., 2018).

The CCS programme in the United Kingdom (UK) offers screening for people with a cervix aged 25–64 years old, or after age 64 if the person has never attended screening or if their last test showed abnormal changes (Public Health England, 2021). Cervical cancer is caused by abnormal cell changes due to the human papillomavirus (HPV). If left untreated, the abnormal cell changes may develop into a tumour (Cancer Research UK, 2020). The HPV vaccination programme, which aims to protect people from the transmission of HPV, has significantly reduced mortality since its introduction in 2008 (Crosbie et al., 2013). However, the vaccine can only pro-

tect against 70%–80% of cervical cancer, meaning that screening is recommended regardless of HPV vaccination status (Crosbie et al., 2013; Harb et al., 2019).

Regular cervical screening saves lives. Screening detects early changes in cervical cells, which can then be treated to prevent development of cancer (Public Health England, 2021). Additionally, screening can halt disease progression as early detection means treatment can begin sooner (Crosbie et al., 2013; Cancer Research UK, 2020), reducing the risk of cancer spreading (Burns et al., 2007), and thus resulting in better patient outcomes. This reduces the risk of mortality and ongoing physical and psychological issues suffered by cancer survivors who receive treatment later, such as bladder and bowel dysfunction or dyspareunia, which can affect their quality of life (Burns et al., 2007).

Additional risk factors for acquiring HPV and developing cervical cancer include smoking and sexual violence, which trans people report higher rates of (Gatos, 2018); therefore, it is imperative to improve the uptake of CCS among TMNB. However, increasing the uptake requires understanding TMNB experiences of cervical screening to develop and implement changes to improve patient experiences of CCS and ultimately make CCS more accessible to TMNB.

|**AIMS AND OBJECTIVES**

The aim of this scoping review is to synthesise research on this topic to provide an overall understanding of TMNB experiences of cervical screening and to identify implications to improve cervical screening experiences and uptake in the future, using the following objectives:

1. To explore what is currently known about TMNB experiences of accessing and attending CCS.
2. To understand factors which affect experiences and uptake of cervical screening among TMNB and to provide recommendations for future improvements.

|**METHODS**

|**Design**

A scoping review was carried out following the framework from Arksey and O'Malley (2005). Scoping reviews are often used in health research on topics with little published literature in order to demonstrate what is known and identify gaps in the literature (Pham et al., 2014). The process involved defining the research question, identifying and selecting studies as described below, charting relevant data, synthesising this data using thematic analysis and finally presenting the data (Arksey & O'Malley, 2005). The Preferred Reporting Items for Systematic reviews and Meta- Analyses extension for Scoping Reviews (PRISMA- ScR) Checklist (Tricco et al., 2018) (Data S1) was also adhered to.

|**Search method**

This section summarises the protocol used for this scoping review.

Database searching was undertaken using key terms and Boolean operators to maximise exposure to the literature between 23/06/23 and 03/07/23. Medline via PubMed, Web of Science, Scopus and CINHAL were systematically searched using key terms, as shown in (Data S2). Key terms were developed using the population, exposure, outcome (PEO) acronym; the population was TMNB, the exposure was CCS, and the outcome was experiences. The search terms (below), included synonyms of the key terms to ensure the search was comprehensive (Arksey & O'Malley, 2005).

TITLE- ABS- KEY ( experiences OR attitudes OR perceptions OR views OR opinions OR qualitative ) AND TITLE- ABS- KEY ( cervical AND cancer AND screening OR cervical AND screening OR pap AND smear OR pap AND test OR smear AND test OR papanicolaou AND test ) AND TITLE- ABS- KEY ( transgender OR trans OR trans AND men OR transmen OR assigned AND female AND at AND birth OR afab OR transmasculine OR nonbinary OR non- binary OR genderqueer OR gender- queer OR gender AND identity OR gender AND diverse OR agender OR bigender OR gender AND non- conforming OR female AND to

AND male OR lgbt\* OR two AND spirit)

Due to the paucity of research in this area, further literature was identified through grey literature and citation searching. Two further studies were also identified following discussion with researchers in the field.

|**Inclusion and exclusion criteria**

Qualitative, quantitative and mixed- methods research were included, and no publication year exclusion criterion was used because there is little published research in this area. For this reason, no geographical restrictions were included; however, papers were only included if they were in the English language.

|**Search outcome**

One hundred and fifty- four papers were identified using this search strategy, and 112 remained once duplicates were removed. The titles and abstracts of the 112 articles were screened, resulting in 81 papers being removed for irrelevance i.e. focusing on other LGBTQ+ identities or other health screening types. The final 31 papers were read in full and scrutinised against the eligibility criteria, resulting in 8 being excluded for focusing on rates of screening uptake or disparities in adequate samples,[[6]](#footnote-6) or focusing on different LGBTQ+ identities. Therefore, a total of 23 papers were included in this review. As this literature review was part of the first author's PhD study, the screening process was led by the first author. The remaining authors contributed to the selection and review of papers during supervision (Figure 1).

**FIGURE 1 – PRISMA diagram of literature selection**A screenshot of a computer

Description automatically generated

|**Data abstraction and synthesis**

Key information from the 23 papers was extracted into a data charting form (Data S3), and the data analysed thematically following guidelines outlined in Braun and Clarke (2022). Analysis involved working in an Excel document to create codes that reflected similar experiences, such as ‘gender dysphoria’ and ‘fear of discrimination’, which were then grouped together to create the three themes presented below. Care was taken to include diverse, contrasting, experiences with each theme. Three authors were involved in the data analysis and any differences in interpretation were resolved by consensus; this helped reduce the risk of selection bias.

|**FINDINGS**

|**Themes**

Three themes were identified, these were: Theme 1–Emotional and psychological distress; Theme 2–Experiences of the healthcare system; Theme 3–Healthcare providers attitudes and behaviours towards TMNB. They are discussed after a description of the studies.

| Description of the studies

Of the 23 papers, 17 were research studies, 11 of which were qualitative (Agénor et al., 2016; Bernstein et al., 2017; Carroll et al., 2023; Dutton et al., 2008; Gibson et al., 2021; Johnson et al., 2016, 2020; Kerr et al., 2020; McDowell et al., 2017; Peitzmeier et al., 2017, 2019), two mixed- methods (Berner, Connolly, et al., 2021a; Potter et al., 2015) and four quantitative (Harb et al., 2019; Roznovjak et al., 2023; Seay et al., 2017; Shires et al., 2019). Three of the papers were literature review articles (Connolly et al., 2020; Dhillon et al., 2020; Gatos, 2018), two were recorded conference presentations (Berner et al., 2021c; Berner, Connolly, et al., 2021b) and one was a conference abstract (Semlyen & Kunasegaran, 2016). Additionally, two research articles, (Bernstein et al., 2017; McDowell et al., 2017), were doctoral dissertations. Grey literature such as conference videos, conference abstracts and doctoral theses were included due to the paucity of literature in the area.

All 23 studies were conducted in the Global North: 13 in the USA, 4 in the UK, 2 in Australia and one in Aotearoa, New Zealand. In the three review papers, all (Gatos, 2018) or the majority of studies reviewed were conducted in the US, with one from France, Canada and Italy (Connolly et al., 2020), and one from Canada and the UK (Dhillon et al., 2020). The majority of participants in each study were aged between 18 and 30 years, non- Hispanic White, TMNB patients recruited from specialist LGBTQ+ services.

Six papers included healthcare professional's perspectives of cervical screening for TMNB, including 60 health professionals from a ‘women's health’ department (Shires et al., 2019), 17 health professionals with experience of caring for trans people (Potter et al., 2015) and 12 key informants on cancer policy, sexual and reproductive health and trans health (Gibson et al., 2021).

| Theme 1–Emotional and psychological distress

Patients and providers consistently reported that TMNB experience physical and psychological distress, discomfort and anxiety when attending, or considering attending CCS (Agénor et al., 2016; Dhillon et al., 2020). TMNB are often aware of the importance of screening for health; however, the emotional distress can be so severe that a significant proportion of TMNB avoid CCS (Dutton et al., 2008). For example, 55% of TMNB patients in Australia reported avoiding CCS due to anticipating the procedure to be emotionally traumatic (Kerr et al., 2020). This is caused by multiple, often interlacing, factors, which are outlined below.

| A history of sexual trauma

CCS can be distressing for anyone with sexual trauma; however, globally, there is a higher rate of sexual trauma among TMNB than cisgender women (Gibson et al., 2021); therefore, it is important to understand how this affects CCS in order to improve uptake and experiences among TMNB.

TMNB patients with sexual trauma often reported negative experiences including distress, a loss of control and PTSD- like symptoms during CCS (Bernstein et al., 2017). Some TMNB also shared that sexual trauma prevented them from attending screening due to fear surrounding the invasive nature of the procedure (Carroll et al., 2023). Additionally, many participants discussed worries of being touched by a stranger or being ignored if they needed the procedure to stop (Bernstein et al., 2017). In one study, the idea of penetration was extremely distressing to a participant, so the use of the speculum meant they were not able to access screening (Johnson et al., 2020). This participant had scheduled multiple CCS appointments; however, had cancelled them due to fear and anxiety (Johnson et al., 2020).

| Heightened gender dysphoria before, during and after cervical cancer screening

Gender dysphoria, which refers to the distress caused by the incongruence between gender identity and sex assigned at birth (Johnson et al., 2016), was consistently discussed across the literature and was reported as one of the primary reasons for delaying or avoiding cervical screening (Carroll et al., 2023; Roznovjak et al., 2023).

Some TMNB experience gender dysphoria throughout their everyday lives; however, it can be exacerbated by CCS due to the focus on genitalia (Berner, Connolly, et al., 2021a; Johnson et al., 2016). One participant stated that the focus on their genitals during screening left them feeling like they were pre- transition as they felt as dysphoric as they did before receiving gender- affirming care (Peitzmeier et al., 2017).

Additionally, TMNB patients can feel uncomfortable with the practitioner seeing their genitalia as this means the practitioner is aware they do not have a traditionally male body, which may not be the case in their everyday lives (Peitzmeier et al., 2017). Some participants also reported that the physical contact during CCS heightens their dysphoria (Carroll et al., 2023; Dutton et al., 2008). As a result, TMNB report feeling dysphoric, vulnerable and exposed during screening (Peitzmeier et al., 2017).

Gender dysphoria can also be triggered by correspondence about CCS, including being sent an invitation, booking an appointment, or discussing the need to access CCS (Berner, Connolly, et al., 2021a, 2021b; Dhillon et al., 2020). This is due to CCS being seen as a ‘woman's exam’, so such correspondence reminds the patient that they have anatomy that is incongruent with their gender (Dhillon et al., 2020). Many TMNB also report feeling worried about being outed by the screening invitation, which refers to other people discovering their trans status, due to seeing that they require CCS (Berner, Connolly, et al., 2021b).

Heightened gender dysphoria can continue to be experienced following the procedure (Bernstein et al., 2017). For example, CCS may lead to disturbing after effects such as vaginal bleeding (Dhillon et al., 2020; Potter et al., 2015). One participant reported experiencing severe pain during the procedure and bleeding for 2 days following, which caused menstrual dysphoria, trauma, and avoidance of future CSS (Bernstein et al., 2017). This participant had called for the procedure to stop; however, the practitioner had ignored this request.

Additionally, the thought of developing cervical cancer can be distressing for many TMNB (Connolly et al., 2020). One participant stated that having cervical cancer would lead to dysphoria so intense that it ‘would kill me as much as the disease would kill me’ (Peitzmeier et al., 2017: p2144). This means that TMNB must navigate the risks of discomfort caused by CCS, along with the risks of developing cervical cancer and the distress this would cause (Connolly et al., 2020; Peitzmeier et al., 2017).

However, dysphoria is not a homogenous experience among TMNB during CCS. Some participants do not experience dysphoria during CCS (Connolly et al., 2020), while others report that their dysphoria during CCS has reduced as they progress further into their transition (Bernstein et al., 2017; Peitzmeier et al., 2017). Furthermore, Peitzmeier et al. (2017) p2140 suggests that people who identify as more masculine, such as transgender men or masculine- leaning nonbinary people, may experience more severe gender dysphoria as compared with people who identify further away from the masculine end of the spectrum (Peitzmeier et al., 2017). This is further evidenced in Kerr et al. (2020) which found that trans men in Australia were much less likely to attend screening than gender diverse people. Additionally Peitzmeier et al. (2017) suggests that gender dysphoria may be less severe in people who are able to view CCS as gender neutral, thus suggesting the extent of gender dysphoria can be influenced by where both identity and perception of the procedure are placed on a masculine- feminine spectrum.

Some participants report that they have become more comfortable in their bodies and no longer feel dysphoria during CCS (Bernstein et al., 2017). One participant stated that a bad experience during CCS would not cause gender dysphoria or affect their self- esteem as they are affirmed and accepted by themselves and other people in their life (Bernstein et al., 2017). However, a participant who was not accepted by their family discussed feeling intense dysphoria during screening as they feared that the practitioner have a similar reaction (Bernstein et al., 2017). Therefore, the extent of gender dysphoria experienced during CCS may be affected by how the participant views their own body, and how their body is viewed by others (Bernstein et al., 2017; Kerr et al., 2020).

| Theme 2–Experiences of the healthcare system

Many systematic barriers to CCS for TMNB were identified

(Bernstein et al., 2017; Gibson et al., 2021). This theme explores the impact of the way the health system can affect TMNB experiences of screening, for example, often TMNB who are registered as male on health records in the UK, US and Aotearoa do not get invited to CCS because current systems do not recognise that TMNB may require CCS. This, among other issues, which are outlined below, has resulted in trans patients reporting feelings of discomfort and distrust within health services.

| Feeling ignored and invisible within healthcare

Globally, TMNB have often been excluded from CCS policy, provision and research, resulting in some TMNB feeling ignored within CCS (Agénor et al., 2016; Gibson et al., 2021). For example, many TMNB participants discussed their frustration at the lack of research and guidelines around CCS in the US (Agénor et al., 2016). Contrastingly, the Australian national CCS program recently began using gender- inclusive language and recommending screening for all people with a cervix (Kerr et al., 2020). At the time of publishing, 44.6% of participants in an Australian study had never been recommended screening but this change was expected to improve the uptake of CCS across Australia (Kerr et al., 2020).

The lack of inclusion of TMNB in discussions of CCS means that some TMNB patients are unaware that they are at risk of cervical cancer, or may feel like their health is at risk and seen as less important than that of cisgender women (Agénor et al., 2016). Some participants navigated worries about their gynaecological health by regularly attending screening, such as one man who stated that regular screening helps him to feel safe and healthy (Agénor et al., 2016). However, due to the uncomfortable nature of CCS, the lack of awareness of the need for TMNB to access screening, and the unwillingness of some providers to screen TMNB, many TMNB do not attend screening (Agénor et al., 2016; Berner, Connolly, et al., 2021b).

Furthermore, many TMNB report distrust in the healthcare system (Bernstein et al., 2017). For example, health services and health insurance companies may only cover CCS for people registered as female on their health records (Bernstein et al., 2017; Connolly et al., 2020). This means that many TMNB patients are unable to change their gender marker as they would no longer be able to access CCS; therefore, the inability to align their legal gender with their gender identity is a direct result of the healthcare system (Bernstein et al., 2017). Because of this, many TMNB view healthcare as an impediment to their transition (Peitzmeier et al., 2017). Some health services and insurance companies state that people registered as male on their health records cannot access pap smears due to ‘gender incongruence’, referring to screening only being needed among women, which ignores that women are not the only people with cervixes (Bernstein et al., 2017). Additionally, in the UK, labs often fail to process cervical samples from TMNB due to having a male name on the form (Berner, Connolly, et al., 2021b). This can be reiterated by providers reporting the results, as evidenced by one trans man in the US who was told ‘This is, can't be for you. You don't have a vagina.’ (Gibson et al., 2021). This was stated in front of the waiting room, causing the patient to feel extremely uncomfortable, and he never received his results (Gibson et al., 2021).

| Perception of CCS as a ‘woman's procedure’

Historically, CCS has been seen as a woman's procedure, despite its importance for everyone with a cervix (Kerr et al., 2020). Levels of comfort often depend on whether providers affirm their patient's gender identity during screening, and whether patients are able to view CCS as gender neutral (Peitzmeier et al., 2017). Health services can (un)intentionally reinforce the feminisation of the procedure in many ways (Peitzmeier et al., 2017). For example, many health services refer to CCS as a ‘well women's exam’, which excludes TMNB (Peitzmeier et al., 2017), and resources such as leaflets and pamphlets are aimed at cisgender women, which reinforce that they are not open to other identities (Dhillon et al., 2020).

The gendered nature of many health settings can be uncomfortable and dysphoria inducing, which can make accessing healthcare as a TMNB difficult. This is especially true when seeking sexual/ reproductive healthcare such as CCS. Some TMNB patients report avoiding appointments at gynaecology clinics due to feeling unwelcome as a result of the non- inclusive environment (Harb et al., 2019). TMNB patients report feeling more comfortable when they are not the only TMNB in the waiting room. For example at trans- specific health clinics, or clinics which set aside appointment blocks specifically for trans people (Dhillon et al., 2020; Johnson et al., 2020).

Many TMNB reported feeling uncomfortable or misunderstood when making CCS appointments by providers and receptionists who discourage or turn away TMNB from attending CCS due to their gender identity and the misconception that CCS is for women only (Berner, Connolly, et al., 2021a, 2021b). Additionally, TMNB may feel uncomfortable when signing non- inclusive intake forms, such as only having ‘male’ or ‘female’ options on gender questions (Dutton et al., 2008). This reminds TMNB patients that healthcare services are not inclusive (Peitzmeier et al., 2017).

| Theme 3–Healthcare provider attitudes and behaviours towards TMNB

TMNB have consistently reported that the attitudes and behaviours of healthcare providers can greatly impact their experiences of CCS. For example, in Aotearoa, 30% of those who delayed screening did so due to worries of how they would be treated by HCPs (Carroll et al., 2023). This theme discusses how HCPs can impact TMNB experiences of CCS, both positively and negatively.

| Discrimination by healthcare providers

Due to worries about adverse experiences with healthcare providers or services, many TMNB opt to access trans- specialist clinics for CCS in the UK and US (Berner, Connolly, et al., 2021a; Dhillon et al., 2020; Peitzmeier et al., 2017). There is a lower uptake of CCS among patients who are not connected to LGBTQ+ competent clinics (Seay et al., 2017). TMNB report feeling more comfortable attending CCS at a trans- specialist health clinic as the providers have a better understanding and experience, meaning trans people feel less anxious about stigma or discrimination (Berner et al., 2021c). For example, all those who reported a positive experience of CCS in a study by Harb et al. (2019) were screened in LGBTQ+ clinics or by a provider who specialised in trans healthcare. Furthermore, a service for TMNB to access CCS was piloted in the UK in which 12/20 patients who were screened there said they would not have accessed screening if the clinic had not existed (Berner, Suchak, et al., 2021). However, many TMNB patients have reported positive experiences with non- specialist providers who carry out the procedure with patience and understanding, and provide good aftercare (Berner, Connolly, et al., 2021a).

In contrast, some TMNB report negative experiences caused by a lack of sensitivity towards, and education on, trans issues among HCPs (Carroll et al., 2023; Peitzmeier et al., 2017). For example, some participants reported being referred to by their deadname in a waiting room (Dhillon et al., 2020), which can exacerbate the distress already felt by being the only masculine- presenting person in a room full of cis women. Further, some healthcare workers take a long time, and require multiple conversations with TMNB patients about their identities, to accept and acknowledge different gender identities, which can create concern among patients that requesting CCS would result in them being viewed as less masculine (Berner, Connolly, et al., 2021a).

Previous negative experiences with medical professionals, both within and outside of CCS creates distrust among HCPs and results in TMNB anticipating further negative experiences in CCS (Johnson et al., 2020; Potter et al., 2015). A higher level of discrimination both in healthcare and everyday life is associated with avoiding health services due to a fear of how providers will treat them (Johnson et al., 2020). This can cause worry about disclosing their trans identity to HCPs due to concerns of how they will react (Dutton et al., 2008), which may affect whether patients feel comfortable requesting a CCS appointment (Johnson et al., 2020). For example, one participant changes their gender expression to present as female to avoid transphobia when attending screening (Johnson et al., 2020). Therefore, HCPs behaviours and attitudes towards trans people and their bodies play a key role in influencing whether patients will attend screening, and whether they have a positive, neutral or negative experience (Gatos, 2018; Kerr et al., 2020).

Many TMNB patients reported that providers had ignored their calls for the screening exam to stop due to discomfort or distress, which they described as a violation or compared it to rape (Peitzmeier et al., 2019). Additionally, some participants felt unable to tell the practitioner to stop, and instead carried on with the procedure despite discomfort (Peitzmeier et al., 2019). This highlights that the experience of CCS can be made significantly worse if health professionals do not listen to the needs or requests of their patients.

| Provider's capability and willingness of providing care to trans people

Despite 85% of CCS providers in a US study stating that they would be willing to screen transgender patients, many TMNB patients report difficulties finding HCPs who do so (Shires et al., 2019). Several patients have been turned away from screening by practitioners who said they had no experience with TMNB patients (Bernstein et al., 2017). One TMNB patient reported negative experiences with overtly transphobic HCPs, and worried CCS would provide practitioners another opportunity to attack them (Berner, Connolly, et al., 2021a). This is a significant issue as practitioners play an important role in CCS access; for example, 38% of TMNB participants in an Australian study did not access CCS due to an inability to find a provider they felt comfortable with (Kerr et al., 2020). Furthermore, Shires et al. (2019) found that only 40% of the providers in their US based study had screened a transgender patient in the past 5 years, suggesting that despite willingness to screen trans patients, many providers have no experience. As discussed in Gatos (2018), this is potentially due to practitioners being willing to screen TMNB but not feeling like they had enough knowledge to do so appropriately. This can create further worry among trans patients who, as above, would prefer a practitioner with experience caring for trans patients (Dhillon et al., 2020; Peitzmeier et al., 2017).

TMNB report positive experiences of CCS when their providers show respect and sensitivity towards their gender identity (Dhillon et al., 2020; Semlyen & Kunasegaran, 2016), which can be demonstrated by using the correct pronouns and terminology, and not making inappropriate comments about their identities or bodies (Johnson et al., 2020). For example, some TMNB patients reported that practitioners who affirmed their gender identity reduced both their levels of discomfort and dysphoria (Dhillon et al., 2020). Additionally, providing further training on working with trans people, such as including different bodies in medical textbooks, can improve providers' understanding of trans issues and the respect and sensitivity shown to trans patients. Whilst waiting for training to be implemented, providers should make effort to inform themselves about best practices for trans+ health.

However, some providers are not only inexperienced in practice, but also report unwillingness to provide healthcare for TMNB. Shires et al. (2019) found that a lack of training and knowledge was not associated with unwillingness to provide CCS to TMNB patients, but bias and beliefs about transgender people was. Therefore, it is important to tackle transphobia among healthcare providers to mitigate negative beliefs about trans people before providing them with training and education around trans health (Shires et al., 2019).

|**DISCUSSION**

This scoping review provides one of the first comprehensive accounts of TMNB experiences of CCS from both a patient and provider perspective. This review highlighted a myriad of negative experiences suffered by TMNB when accessing CCS. Many of these were similar to those of cisgender women such as worries around physical pain, sexual trauma, and embarrassment; however, experiences unique to TMNB were also shared (Berner, Connolly, et al., 2021a; Dhillon et al., 2020; Kerr et al., 2020). Circumstances such as experiencing poverty, homelessness or sexual assault, or being neurodivergent are associated with a lower uptake of CCS, and are also more common among TMNB (Kerr et al., 2020).

The findings highlight how TMNB are often subject to negative experiences with CCS due to trans- specific barriers. For example, TMNB often experience a higher level of pain during screening due to testosterone use which causes vaginal atrophy; the thinning and drying of vaginal walls which can increase pain during penetration (Berner, Connolly, et al., 2021a). Additionally, TMNB may experience gender dysphoria due to the focus on genitalia and may feel heightened embarrassment at HCPs seeing this area of their body (Connolly et al., 2020; Weyers et al., 2021). Furthermore, TMNB are less likely to provide adequate cervical samples which may mean they need to repeat the potentially distressing procedure (Gatos, 2018; Reisner et al., 2018). This highlights the need for trans people to be given equal but not identical care (Caulfield et al., 2016).

Trans people often experience additional systematic barriers to CCS. For example, all people registered as female with their GP automatically receive an invitation every three years; however, trans men who are registered as male do not receive this invitation despite potentially needing this service (Public Health England, 2021). Additionally, GP systems tend to offer binary gender classifications which means gender diverse people have to select ‘male’ or ‘female’. This means that not all TMNB receive an invitation to screening, which shows that the current invitation system is a barrier to accessing screening (Public Health England, 2021). This systematic denial of the existence of trans people creates distrust within the healthcare system, which can be further exacerbated when undergoing uncomfortable procedures such as CCS (Bernstein et al., 2017).

|**IMPLICATIONS**

This review indicates important implications for healthcare services and education. Positive experiences result from accessing trans- specific screening clinics, or providers who behave in a sensitive and respectful way with patients. This shows that the attitude providers have towards trans patients can affect experiences of CCS; therefore, improving health education is required (Roznovjak et al., 2023). This should include teaching providers to discuss options with their patients which may ease physical and emotional discomfort (Potter et al., 2015), such as offering self- insertion, to be accompanied by a trusted friend, and improving trauma informed care. Additionally, education on appropriate behaviour is required, such as avoiding heteronormative assumptions or inappropriate curiosity. Improving education on trans+ health will also help to reduce potential biases or prejudices, whether conscious or unconscious, held by HCPs, which in turn will improve trans+ peoples experiences of, and trust in, health services.

Furthermore, TMNB patients report feeling more welcome when they are represented in clinics, waiting rooms or correspondence (Dhillon et al., 2020). Therefore, the use of inclusive policy documents, indicators of being trans friendly such as including trans+ people in leaflets, posters or invitation letters, or offering gender neutral bathrooms, can help TMNB to feel included and comfortable when accessing CCS (Potter et al., 2015).

Lastly, removing systemic barriers, such as updating the current invitation system to ensure that TMNB who are registered as male receive an automatic invitation to screening, would make the procedure more accessible, and thus improve the overall experience and future uptake. Electronic systems should also be updated to ensure that contact with patients uses their correct name, pronouns, titles and gender (Carroll et al., 2023). Therefore, multiple changes within the health services are required at a systematic and societal level, which may in turn improve TMNB's experiences of CCS.

|**Limitations**

The lack of published literature in this area is a potential limitation of this review as many TMNB experiences have not yet been captured. Additionally, 3 papers (Agénor et al., 2016; Peitzmeier et al., 2017, 2019) and a further paper and conference abstract (Berner et al., 2021c; Berner, Connolly, et al., 2021b) used data from the same participants which potentially limits the diversity of participants included in this review. Additionally, of the six papers which included providers, three (Agénor et al., 2016; Bernstein et al., 2017; Peitzmeier et al., 2019) used the same 17 providers recruited from a trans- specialist clinic, which limits the diversity of providers discussed in this review. Furthermore, the research on provider perspectives required providers to be interested in research about trans health. This is a potential sample bias because those with negative feelings towards TMNB may not have responded to calls for participants. Additionally, all research with providers was undertaken in the US and Australia, both of which are relatively accepting of trans people (Flores, 2021). Therefore, studies on provider perspectives in cultures that are less tolerant of TMNB were not captured.

Requiring research to be published in English language may also have excluded research from other countries. While this review did not impose any geographical exclusion criteria, all the research took place in the Global North, which means TMNB people from the Global South are not represented. TMNB living in countries with less tolerance towards LGBTQ+ people may experience adversity when accessing CCS or may be denied this altogether. Further, although some researchers made efforts to recruit a diverse group of participants, such as Peitzmeier et al. (2019), who aimed to recruit older trans patients and trans people of colour, the majority of participants in this review were white and young (aged under 30); therefore, the experiences of older adults or people of colour may not be represented. Until the research evidence base grows, primary studies could ensure that a diverse group of participants are recruited, such as by recruiting from settings outside of trans- specific clinics and recruiting people with multiple marginalised identities to create a wider understanding of TMNB experiences of CCS.

Conclusion

This review has highlighted the ways in which CCS often fails TMNB people. Individual barriers, such as gender dysphoria, can be exacerbated by systemic barriers that make practical aspects of accessing cervical screening difficult. Improving trans peoples experiences with and uptake of CCS should involve a multi- level approach including medical education about trans health, health service policy change such as modifying the procedure to make it more appropriate for different bodies, as well as societal change in attitudes towards trans people.

**AUTHOR CONTRIBUTIONS**

Georgia Rivers conceptualised the project as part of a PhD programme of study supervised by Professor Sharron Hinchliff and Dr Jill Thompson. The literature review type was discussed and decided by all three authors. The literature search was conducted by Rivers who analysed the data with input and guidance from Hinchliff and Thompson. Rivers wrote the first draft of the literature review paper which was refined and edited through discussions with the co- authors.

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**CONFLICT OF INTEREST STATEMENT**

No conflict of interest for any author.

**DATA AVAILABILITY STATEMENT**

Research data are not shared.

**ETHICS STATEMENT**

In accordance with the journal policy and our ethical obligation as researchers, we are reporting that we have no conflicts of interests relating to this paper. This review was undertaken as part of a self- funded PhD and received no other funding.

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**SUPPORTING INFORMATION**

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## Appendix 2- A table of the key terms used in the search strategy

|  |  |  |
| --- | --- | --- |
| Table of Key Terms | | |
| Population | Exposure | Outcome |
| Transgender, trans, trans men, transmen, assigned female at birth, AFAB, transmasculine, nonbinary, non-binary, genderqueer, gender-queer, gender identity, gender diverse, agender, bigender, gender non-conforming, female to male, LGBT\*, two spirit. | Cervical cancer screening, cervical screening, pap smear, pap test, smear test, Papanicolaou test. | Experiences, attitudes, perceptions, views, opinions, qualitative |

## Appendix 3 – PRISMA diagram of literature selection

Papers identified by:

citation searching n=4

grey literature search using BASE: n=1

conversation with academic in area : 2

Titles/Abstracts

screened

n=112

Papers excluded due to non-relevance n=81

Reasons:

Focused on other LGBTQ+ identities, focus on other screenings, focus on disparities in adequate swabs, focus on other areas of health care

Full papers assessed for

eligibility

n=31

Full text papers excluded n=8

Reasons:

Focus on adequacy of samples or rates of screening, focus only on LGBTQ+ women, looking at interactions between medical students and trans patients.

Studies included in literature

review

n= 23

Papers identified through database searching

n=154

Papers after duplicates removed

n=112

## Appendix 4 – Data charting sheet

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Author and year** | **Country** | **Aims** | **Sample** | **Methodology/ methods** | **Critical analysis** | **Key findings** |
| Agenor et al (2016) | USA | To explore the perceptions of risk of HPV and cervical cancer among transmasculine individuals and HCPs to see how these risk perceptions may affect ccs uptake. | 49 participants (32 transmasculine patients and 17 healthcare providers). HCPs recruited from Fenway Health. HCPs must have conducted at least one pap test on a transmasc individual. Purposive sampling to select transmasculine people aged 21-65 who had not had a hysterectomy through Fenway Health, Boston Pride, social media and community groups. | 32 in-depth, semi-structured interviews with transmasculine participants and 3 focus groups each with 5 providers. Interviews were audio-recorded and lasted between 60-125 minutes. Audio-recordings were transcribed verbatim and analysed using grounded theory principles. | Informed consent from all participants. Same interviews and focus groups as Bernstein (2017). Participants taken from trans health service, may skew experiences to be more positive than those not connected with trans specialists. | No guidelines for ccs among transmasculine individuals in US, so there are differences among who providers invite for screening.  Some patients view testosterone use as a risk factor for CC, suggest that people on testosterone may need to be screened more often. Some patients were uncertain on risk of testosterone on CC and some stated there was no increased risk.  Several participants discussed frustration at lack of research around CC in trans people.  Some participants managed the lack of knowledge by getting tested regularly, one stating that attending CCS helps him to feel safe.  A provider stated that some of her patients were unaware that they were still at risk of CC. Some providers discussed distress, discomfort, anxiety and fear that their transmasc patients have experienced during/ about CCS discussions and suggest it needs to be modified to accommodate them e.g.// self insertion. |
| Berner et al (2021)a | UK | "To understand the attitudes towards and preferences for cervical screening among UK-based TMNB." | 137 participants, 80% transmasculine, 18% nonbinary, rest identify as other non cis gender identity. Patients of 56T (trans specific sexual health service), and the largest GIC in London were sent email invitations. | Cross sectional questionnaire with 75 questions. Optional free text questions for further details. Mixed methods study - quantitative results analysed with descriptive statistics and free text analysed using thematic analysis. Age above 18 - important to include people approaching CCS age. | Development of survey guided by PPI focus groups run by Jo's Trust and LGBT foundation, and drafts sent to GIC and 56T for review. Participants taken from trans specific services, Potential bias as trans people who do not engage with these services were not included. | 64 participants were eligible for CCS and of them, 37 had attended. 24 of the 37 had delayed at least once.  8 of the 64 had never received a screening invitation. "I changed my gender marker to male so I'm not invited at all anymore".  Feeling misunderstood by receptionists when trying to book a CCS appointment due to gender identity. 9 participants discouraged and 1 turned away from attending CCS due to gender identity.  Majority of participants worried about dysphoria. Barriers to attending include not liking to think about genitals, difficult questions, concerns for dysphoria and unprofessional behaviour, fear of how others may react to gender identity, not wanting to disclose gender identity, having to be expert in own health, past bad attitudes to trans people, risk of assault and not wanting a cis practitioner.  One participant has had negative experiences with two practitioners who were opposed to the existence of trans people and was worried that screening would provide another with the opportunity to assault them.  One participant worried about the time taken for HCPs to recognise them as male and that requesting CCS would make them view them as less masculine. Worried about dysphoria related to procedure & correspondence e.g.// people seeing that part of body, having to think about that part of body and invitations/ venues being very women-focused e.g.// use of she/her, feminine design and language etc.  One participant sent home with speculum to practice feeling comfortable with insertion. Feel more comfortable at a trans clinic due to knowledge they're doing their job not just doing it out of curiosity. Positive experience with non-specialist nurses were also reported e.g.// being patient and understanding, providing good aftercare  Some worried about reminders causing dysphoria where others thought reminders were good so they did not forget to book. Some barriers are shared with cis women and some are unique to TMNB. |
| Berner et al (2021)b | UK | To explore the barriers and facilitators of CCS in the UK. | 137 TMNB people AFAB in the UK aged 18 or over. Recruited via email lists of gender identity clinic and specialist trans sexual health service. | Descriptive questionnaire study of cervical cancer screening and gynaecological care among TMNB. Quantitative analysis of categorical questions and thematic analysis of free text questions. Majority of respondents were under age of screening, felt important to include attitudes from people almost eligible | Email lists of gender identity clinics and specialist trans sexual health service, may miss out those who aren’t connected with either / who aren’t out. | Labs frequently fail to process cervical screening samples from TMNB in UK due to male name on the form, so the GP has to communicate with the lab to ensure results are sent.  Majority of respondents were under age of screening, felt important to include attitudes from people almost eligible. Of those eligible to be screened, only 56% had ever attended. 31% of attendees reported a negative experience but were more likely to reattend than those who had never attended, suggests that knowing what is involved in the procedure even if it has been negative makes future screening more likely. 7% had been turned away from screening due to gender identity.  Worries about being outed by invitations for screening, but half thought it was good to be reminded to attend. Worries of doctors or nurses acting unprofessionally.  Speculum is most offputting part of ccs for TMNB.  Continues to be an area of unmet needs among TMNB in UK, ameliorating this would improve incidence of cervical cancer and rates of survival among these groups. |
| Berner et al (2021)c | UK | A video conference on the cervical cancer clinic pilot of the no barriers cervical cancer screening project which aims to ameliorate access to and experiences of cervical cancer screening among TMNB. | 44 TMNB patients were screened in the pilot study and 20 TMNB completed service evaluations. | Conference video on pilot clinic. Weekly cervical cancer screening clinic for TMNB to gauge acceptability and usage of clinic and explore how best to promote the service. User experience and social media campaign were analysed. | Conference presentation. Shared on social media to get as many participants as possible. | 12/20 TMNB who filled in the service evaluations said they would not have attended ccs if the clinic did not exist.  9/20 said they would attend if their GPs offered a similar service. Prefer to access cervical cancer screening at a trans specialist health clinic due to better understanding of procedure for trans people and better understanding of trans issues meaning they felt less fearful of stigma or discrimination.  Feedback was 100% positive so looking to extend the service to other GP centres. |
| Bernstein (2017) | USA | Aim to highlight how gender and power dynamics in cervical cancer screening affect transmasculine peoples experiences and uptake of CCS. | 116 transmasculine patients and 17 health care providers. Participants recruited from Fenway Health (a health and research facility in Boston, Massachusetts that specializes in the primary care of sexual orientation and gender identity minority individuals), social media, community organisations which serve transgender people and Boston Pride 2013. Trans participants aged 21-64 as per US CCS guidelines. | trans patients completed in-depth interviews(n=32), patient online surveys(n=84) and providers participated in focus groups (n=17 in 3 focus groups). Qualitative grounded theory approach. Interviews lasted between 60-125 minutes. Interviews were audio recorded and transcribed verbatim then analysed using principles of grounded theory - focused coding and thematic analysis. Survey included both open and closed questions and was included so that participants who felt uncomfortable discussing experiences face to face could be involved. | Same participants used in multiple research papers but with addition of 84 online patient surveys. | Participants felt more comfortable when providers affirmed their gender - "you're still a dude and you're doing this thing that’s important for your body".  Expressed feeling "not visible and not seen" in health care due to the way it is set up to ignore trans people and trans bodies.  Several participants who had changed marker were denied health insurance coverage of pap smears due to "gender incongruence" - denies existence of trans bodies  Participants with a history of abuse often feel a loss of control and experience PTSD symptoms, discuss difficulties with somebody touching them and worries of telling them to stop and not being listened to.  Previous negative experiences make people not want to reattend, e.g.// a 22 year old trans man who experienced severe pain and bled for 2 days following screening - had been ignored when asked to stop and wasn’t told he was bleeding.  One participant discussed that passing in everyday life made it easier for them to attend CCS as he was able to feel more comfortable in his body due to passing.  Another said one bad experience (referring to ccs) wouldn’t change their opinion of themselves due to being accepted by people in their life and feeling more confident in their body.  Participant who was not accepted in everyday life e.g.// by family found it more difficult due to fear that another person would see their body as "grotesque or sinful".  Felt uncomfortable and pain, did not like that process wasn’t explained before the procedure.  Consent form before procedure says "women’s name" and "women’s date of birth" - find it frustrating because using gender neutral "patient" instead of woman would suffice.  One participant discussed preferring different terminology to refer to their genitalia as hormones have changed their body so this area is no longer the traditionally female body and thus shouldn’t be treated that way e.g.// use non specific terms such as "inside" or "parts" rather than "vagina" or "vulva". Feel dysphoric about vaginal penetration, described CCS as "consenting to be raped".  Felt happier when CCS is referred to as something that people with a cervix do rather than something that women do.  Nine TM participants reported their calls to stop being ignored.  Several participants were turned away from practitioners who said they had no experience with trans patients. |
| Carroll (2023) | Aotearoa, New Zealand | Identify barriers to uptake of cervical screening for trans+ people in Aotearoa | 318 TGNB people assigned female at birth aged 20– 69 years who had ever had sex. Still majority white (73% New Zealand European/Pākehā) but also 15% Māori and rest made up of Pacific Islander, Asian and Other including Middle Eastern/Latin/ African | The 2018 Counting Ourselves data were analysed to report on experiences of those who were eligible for cervical screening (n = 318). Recruited from social media, networks connected with TGNB people and health professionals working in trans health, had 1178 respondents. This study used the responses about cervical cancer screening - 318 AFAB trans people who had ever had sex aged between 20-69. | Survey only asked about experiences in the last 12 months so some experiences of screening wont have been shared. Also the rates won’t be accurate because it only asks about the last year but some people won’t be called back as you only need to go every 3 years. | For those who had delayed cervical screening, 30% did so due to feeling worried about how they would be treated as a trans or non- binary person. Other reasons for delay related to general and gender- related discomfort, previous traumatic experiences, anxiety or fear of the test and pain.  Material barriers to access included cost and lack of information.  The current cervical screening program in Aotearoa does not consider the needs of TGNB people, leading to delayed and reduced uptake of cervical screening.  Health providers require education on the reasons TGNB people delay or avoid cervical screening in order to provide appropriate information and affirmative healthcare environments.  Some described anticipating that dysphoria would be heightened by the physical contact involved in the screening process; as one participant put it, ‘I don't like having my genitals touched, especially if I am in a dysphoric. Some participants put off screening due to dysphoria for years.  Impact of previous trauma after non- consensual medical procedures, or disrespectful or in- appropriate treatment in healthcare settings. Some participants also disclosed that past sexual trauma pre- vented them from being screened, and these experiences increased distress or fear around the invasiveness of cervical screening.  Find screening more painful when since starting hormones.  Not being able to afford it, not knowing enough about screening and whether they need it, not receiving an invitation due to not being marked as female. Health systems can also update electronic systems so that recall letters use correct names, titles, pronouns and gender details, and ensure that staff are trained to avoid the negative impacts of misgendering. |
| Connolly et al (2020) | Mostly US studies with one paper from Canada, Italy and France. | A literature review to synthesise papers looking at barriers and facilitators of cervical cancer screening among transgender men and nonbinary people to inform changes in UK policy and clinical practice. | 27 studies looking at trans and nonbinary screening. 20 quantitative, 4 qualitative, 3 mixed methods. | Systematic narrative review. Systematically searched using databases for relevant papers, two researchers screened abstracts and titles for inclusion independently, | Mostly quantitative, mostly US, one paper from Canada, Italy and France | Some participants found the need to focus on feminine parts of their body upsetting and some found removal of gender affirming clothing such as binder or prosthesis to be upsetting. Discussion of developing cervical cancer as extremely distressing for trans people, which can act as a motivator to attend screening despite the worries of this in order to prevent future illness. Provider knowledge and comfort in providing screening or general care to trans people is variable, e.g.// some providers are aware that CCS can be more painful for trans people due to testosterone use which can cause vaginal atrophy and thus make modifications such as allowing self insertion, or performing less distressing HPV tests before the speculum procedure to see if they need to go through with it. Systemic barriers to screening such as not being invited due to M gender marker or not being covered with health insurance for ccs when registered as male. Trans participants feel pain and dysphoria and often have to attend screening multiple times due to androgen therapy-associated inadequate Pap sample. Patients feel more comfortable when correct pronouns, names for patient and names for their genitalia are used. Other trans patients do not report experiencing dysphoria or pain. Should not assume whether patient will or will not be comfortable but instead ask about their feelings, experiences, concerns and preferences for screening and give them as much control as possible e.g.// self insertion, screening method etc. Most studies involved take participants from specialist LGBTQ+ health services so its not representative of experiences of those attending non-specialist services, which may mean that the review is skewed to more positive experiences due to increased knowledge of providers working in LGBTQ+ specialist services. |
| Dhillon et al (2020) | 13 US studies, 1 Canada and 1 UK | A scoping review which looks at barriers to ccs and experiences of ccs among TMNB to see how these affect uptake and utilisation of CCS | 15 studies looking at barriers and experiences of cervical cancer screening among TMNB | Scoping review, papers found via searching CINHAL, PubMed and google scholar. | 13 US studies, 1 Canada, 1 UK. | experience physical and psychological discomfort, ccs triggering gender dysphoria was consistently reported across all studies, feel a lack of agency and control, gender dysphoria both during procedure and when discussing procedure e.g.// booking appointment or talking about need for ccs, made worse as they have to think about an area which they usually disconnect from and because exam feels incongruous with masculine identity. TM expressed feeling vulnerable—“on show,” “exposed,” or “judged” during the exam. Heightened anxiety around showing genitals in comparison with ciswomen as there are similar worries with the addition of exposure of sexual anatomy that they feel dysphoria and disconnect with as it is associated with their assigned at birth gender. Made worse if other practitioners than the necessary are there as they feel like voyeurs. less dysphoria if they reframed procedure as gender neutral. in addition to physical pain some participants experienced disturbing after effects, e.g.// bleeding following the procedure which created gender dysphoria linked to menstruation, with one participant bleeding for 2 days. reported that providers who were willing to make modifications were able to perform screening with little to no pain. practitioners who affirmed patients gender identity made them feel more comfortable and sometimes helped them overcome dysphoria. reported a power struggle when practitioners refused to make modifications. participants who reported positive experiences in cervical cancer screening had been screened by a provider who specialised in transgender care. hard to find practitioners who were educated/experienced enough in trans health, TMNB often had to explain specific needs to them. felt more comfortable knowing that practitioners were comfortable working with bodies that differed from binary male–female bodies, which are the main/only bodies shown in medical training. some participants were addressed by their legal name instead of their preferred name by receptionists in waiting rooms, caused discomfort especially when in a room of cis women. prefer to attend trans health clinics so they are not the only males in a room of ciswomen. resources aimed at heterosexual cisgender females reinforced that they were not open to other people. feel more welcome when tmnb are represented in the space. |
| Dutton (2008) | USA | Qualitative study looking at gynaecological care experiences of trans men | 6 trans men aged between 19-41 | Face to face interviews following three different questionnaires | Number of years ago, language has changed | 1) receiving annual gynaecological care was perceived to be important; revealing their gender identity to health care providers was a struggle; and the male/female boxes on health intake forms, as well as pronoun usage by medical staff, were barriers to health care, All participants identified a generalized dislike of receiving gynaecological care, but each expressed an interest in maintaining their physical health despite the emotional challenges to receiving care, gynaecological exams are often a unique time when extreme emotional conflict between self-perceptions and physical anatomy are heightened because of physical touch, Checking the male or female box on a health care intake form implied certain aspects of one’s physical body, biologic sex, as well as physical appearance and gender expression. All individuals interviewed had stories of the conflict between the box marked on intake forms and their appearance, name, anatomy, and identity. |
| Gatos (2018) | All 7 studies in USA | Review current literature about cervical cancer screening for trans+ people | 7 papers | Literature review | Only 7 studies, of those 4 recruited sample from an LGBTQ+ health service. | Consistently more likely to have inadequate pap smears. Participants identified Pap testing as a reminder of the female part of themselves and found this upsetting and a reason to avoid gynaecological examinations altogether. Additionally, all participants noted that receipt of care from competent and sensitive providers resulted in positive experiences and increased their likelihood of seeking routine care. Health professionals were willing to screen trans patients but did not feel they had enough knowledge. Health professionals should be trauma informed. |
| Gibson et al (2021) | Australia | A study exploring how providers and policy makers are addressing the needs and experiences of trans and gender diverse people in a cervical cancer screening clinic in Sydney, Australia | 12 key informants in cancer policy, sexual and reproductive health and trans health | 12 interviews undertaken with a diverse range of professionals to get their perspectives on cervical cancer screening for trans people. Worked with LGBT+ organisations to get key informants. Interviews were recorded and transcribed verbatim and analysed using a theoretically-driven inductive thematic analysis. | Provider/ policymaker perceptions rather than from TMNB opinions. | Broad agreement that trans people have been largely invisible in cervical screening policy and provision. Often marginalised, overlooked or excluded from screening policy and provision. Need to de-gender cervix as a woman’s body part as not everyone who has a cervix is a woman and not all women have a cervix, campaigning for all women to be screened excludes cisgender women without a cervix and transgender women. Also recognise socio-political importance of emphasising and advocating for "the importance of ‘women’s health’. I’m using inverted commas." and raising awareness around women’s health and bodies, but also need to recognise issues with this in terms of excluding certain women. " any attempt at promoting trans visibility therefore needs to avoid erasing the historical gains, and ongoing need for, women’s health.". Trans patient, when trying to get their CCS results was told "‘Oh, this is, can’t be for you. You don’t have a vagina.’" to the entire waiting room and never got the results. Experience gatekeeping from ccs and being overlooked as a potential/legitimate recipient of the service. Trauma informed care - creating an environment where participant has total control over what happens when & are able to give consent - best practice for working with parts of the body that cause high levels of anxiety. Could provide longer appointment times, more consultation with the patient during the procedure, and ensuring that practitioners use words that the patients are comfortable with when describing body parts. Pilot clinic service where they met with a peer support worker prior to the procedure where they were talked through the procedure and asked for identifiers such as gender, pronouns, terminology to use for body parts, whether they need a safe word to stop the procedure, whether they want the clinician to talk to them throughout or just get it done. Policy and practice required to tackle issues with "trans visibilities, trauma and trust". |
| Harb (2019) | Midwest USA | Understanding motivators and barriers faced by trans+ people when accessing sexual health care services. | 17 people with a cervix who are trans or non-binary and aged 18 or over. 16 white 1 Latinx. | Quantitative knowledge survey about sexual health care and semi structured interviews about sexual health care experiences. | Participants who had a positive experience accessed LGBTQ+ specific services, amount of positive experiences here is not representative of people unable to access these. Not representative of people in rural/traditionally conservative areas. | Average number of correct answers about sexual health care was 10/14. 59% had received a pap test before - 71% of those who hadn't were due to age, and only 2 were over age and decided against it. 70% described their screening as a positive experience - all of these were screened at an LGBTQ+ clinic or by providers who specialise in trans health care. 57% of the participants under 21 said they would go in the future if given more information. The analysis of qualitative interview data identified one facilitating factor (health care provider’s role and relationship) and three inhibiting factors (availability of transgender-competent care, distress about seeking sexual health care, and characteristics of the health care setting) regarding. Expressed that they would go if a provider told them to but wouldn’t be proactive. Feel more comfortable when they have a good relationship with the provider - not just meaning that a provider is willing to screen but also that they have knowledge of screening trans people, felt comfortable treating them, and could help them to feel comfortable. Avoid non-inclusive places like gynae clinics. Worries that providers don’t know enough about trans identities/trans specific care - have to educate them. Not feeling welcome in gynae clinics. |
| Johnson et al (2016) qual | USA | A qualitative examination of the behaviours of lesbian, bisexual and queer women and transgender men with regards to cervical cancer screening. | 22 interview participants and 226 questionnaire participants. 4 transgender male participants and 21 genderqueer participants. Recruited from Internet, community settings, and word of mouth. Internet based included social media and blogs and community settings involved 2 LBQ events in USA. | "A convergent-parallel mixed-methods research design involving the separate but simultaneous collection of quantitative and qualitative data, followed by the combination and comparison of the 2 resulting data sets". This paper presents findings from qualitative section, which used in depth interviews and online questionnaires. Qualitative data was uploaded to NVivo and analysed using inductive-deductive content analysis. | 22 interviews and 226 questionnaires of LBQ women and transgender men. 4 trans males and 21 gender queer participants, but lots of the findings did not separate what was an LBQ vs TMNB experience so could not be included. | One transgender man stated that going with a trusted friend was "the only thing that worked" for him. Reported that gender dissonance was only difference between LBQ and TM experiences due to incongruence between gender identity and sexual anatomy causing distress. One transgender men reported that "For transmen, needing to focus on an essential female part of themselves is incredibly upsetting". Discussed emotional conflict when thinking of sexual anatomy and the emotional and psychological distress experienced both during screening and when thinking about attending screening. |
| Johnson et al (2020) | USA | Aim to identify determinants of cervical cancer screening from TMNB perspectives | 9 transgender men and 11 genderqueer or gender non-conforming people ages 21–65 | Exploratory qualitative research using semi-structured telephone interviews conducted by researcher with lots of qualitative research experience. Analysis via inductive-deductive content analysis then sorted into a socioecological framework. Analysis undertaken separately by 3 researchers (PI and 2 doctoral students) then compared. | Researcher had a lot of qualitative research experience. Analysis undertaken separately among researchers then compared. | Factors in the following categories: society, health care institution, interpersonal encounters and intrapersonal/individual. Society e.g.// stigma and laws, health care institution e.g.// documentation/records/correspondence, interpersonal e.g.// cultural competency of health care staff, intrapersonal e.g.// past negative experiences, dysphoria, stage of coming out, sexual trauma. Feel more comfortable knowing that the health service is a safe space if they see pride stickers or LGBT posters or if forms use gender neutral language and clinic has gender neutral toilets, know there is some awareness of LGBT/trans issues. More likely to attend CCS if the clinic has cervical screening appointment blocks for trans people. Felt it important that healthcare professionals are aware of and comfortable with working with trans patients and trans bodies and respectful of this e.g.// using correct terminology, pronouns and name. "I just want the doctors, nurses, and staff to treat me like a human being and not get so awkward around me when they discover I am a queer trans man." People who have experienced discrimination in healthcare anticipate more discrimination at CCS, lifetime of discrimination makes people avoid healthcare as they "fear how they will treat me". Trans participant who has experienced sexual assault fears penetration with speculum and has tried to attend multiple times but becomes too fearful and cancels. Gender dysphoria - "its hard to undergo a procedure that reminds me of the body part I hate the most". One participant changed gender expression to present as female to avoid discrimination due to trans identity when attending CCS. Suggests that there is a relationship between stage of transition and coming out process and CCS but needs to be more research to discuss this properly, but trans people towards end of their transition and coming out process often have an improved quality of life, higher levels of self esteem and lower levels of stress, anxiety and depression which may improve feelings towards CCS. One participant said they only felt confident enough to attend CCS once they had fully transitioned as before it felt awkward and difficult and they had little confidence in themselves. Comfort level in disclosing gender identity to HCPs affected whether they attend. Every patient spoke about health insurance and financial situation being important aspects of CCS access. Significantly lower rate of attendance among this sample than general population (55% vs 70%). Important to ameliorate experience of CCS for people who have experienced sexual assault, especially for trans people who experience this more than general population. |
| Kerr et al (2020) | Australia | To explore issues with cervical cancer screening participation among transgender and gender diverse people. | 196 trans and gender diverse (TGD) people with a cervix aged 18 above, Aus screening program begins at 25 but changed from 18 a year before the study began so people under 25 were included as they may have been screened. | Online survey created with input from TGD community. SPSS used to analyse data using descriptive statistics. | Survey created with input from TGD community, can be more sensitive to the population and include things that are important to the group. | 44.6% had never been recommended screening despite being of eligible age. 55% reported not attending due to anticipating the procedure to be emotionally traumatic. 38% reported not attending screening as they were unable to find a HCP they were comfortable with. People with a greater like for their body were more likely to attend screening. High number of people reported experiencing homelessness or being neurodiverse which are factors also related to underscreening. High number of people had not been screened, but 31% had never had sex so may partly explain this as CCS starts following sexual activity. National screening programme of Aus has recently started using gender inclusive language and recommending screening for all people with a cervix rather than just women, this and health promotion may lead to an increasing uptake of ccs. Trans men were less likely to attend screening than gender diverse people. Majority would prefer self swabbing due to less gender discordance, higher sense of agency and less invasive procedure. Healthcare professionals behaviours and attitudes are a key factor of attending screening and having a positive experience when screening. |
| McDowell et al (2017) | USA | Aim is to examine transmasculine peoples preferences and experiences of cervical cancer screening and hrHPV self swabbing and whether self swabbing alone is an adequate option. | 63 transmasculine participants aged 21-65 as per USA cervical screening guidelines. | Transmasculine individuals took part in 31 interviews and 32 online surveys. Modified grounded theory approach with descriptive statistics for quantitative aspects and thematic analysis for qualitative. | Doctoral dissertation. | Participants described the pap test as being uncomfortable, invasive and traumatic. Some participants felt the self-swab would be more comfortable and they'd be more likely to regularly engage with this, but others reported worry with having to redo this if the sample isn’t adequate, and because they feel the pap smear is more robust and feel safer and more secure in their health with this as they also do a visual exam. "You can switch off if someone else does... whereas if you physically have to do it, then you're acknowledging yourself... " - preferring pap smear. Others would rather not have other people see body parts that they feel dysphoric about. More comfortable doing pap smear if they know their provider, but more comfortable doing it themselves if it is a provider they don't know. Many participants stated that frontal sample self-collection would result in less physical and emotional discomfort, improved agency, and reduced gender dysphoria, addressing several barriers to cervical cancer screening adherence for TM individuals. Participants had a higher pap testing frequency than general TMNB population so some stuff may have been missed. Further research should include more diverse TMNB populations, including people of different races/ethnicities/socioeconomic backgrounds to capture the heterogeneity of TMNB experiences. |
| Peitzmeier et al (2017) | USA |  | 32 transmasculine individuals aged 21-65 per screening guidelines. Participants recruited from Fenway Health, an LGBT specialist health service, social media, Boston pride and other community projects that serve trans people | 32 in-depth interviews with transmasculine participants. Modified grounded theory approach. Line by line analysis of verbatim transcribed interviews using focused coding. Coding occurred independently then researchers met to discuss discrepancies and create categories of codes. | Same participants used in multiple research papers. | Health institutions and insurance companies can inadvertently or intentionally feminise patients as they undergo a "well women’s exam" so participants have to negotiate their gender identity with them, comfort and accessibility depends on how well they are able to do this. More comfortable when patients are able to reconcile the procedure as gender neutral rather than feminine. Some participants were able to reframe procedure as self care rather than viewing it as a challenge to gender identity or privacy. “Imagining a spectrum between masculine and feminine, the further the participants’ gender identity was from their perception of the Pap test, the greater the incongruence and psychological discomfort they experienced at the idea of undergoing a Pap test". One man discussed wanting to take care of his health and compared it to undergoing transition, which was difficult but necessary for his health. One gender diverse participant said they do not feel dysphoria with genitals so this doesn’t bother them in terms of ccs but struggled with mammograms due to dysphoria from chest, also discussed that identifying as more masculine may worsen experience due to heightened genital dysphoria. One transman discussed having extreme dysphoria - "When I go in for a check-up, whether or not I’m getting a Pap, I have to deal with the fact that I have the plumbing and the parts of a woman. And, I have to think about that and I hate thinking about it". Having an established relationship with the provider was a facilitating factor as they did not have to worry about coming out to them, worries of having to go somewhere new/with a different provider due to anticipating negative reactions. One participant had been screened previously but would not get screened by his current provider as he did not want to come out to them. Want HCP to have experience and training in "working with trans people and trans bodies". Wanted "cultural competency" - using right names, terminology, pronouns, and an understandings that not all bodies look like those in textbooks. One described going despite discomfort as other health procedures are uncomfortable but necessary for health such as going to the dentist. Some participants felt they had to educate inexperienced practitioners on trans issues. Stories of inappropriate, excessive or invasive questioning about transgender issues such as sexual activity or surgeries which were not relevant to procedure, suggest providers should have to present their level of training and experience with working with trans people and trans bodies so patients can feel more safe and pick experienced HCPs. More comfortable when practitioners modified the exam e.g.// by allowing patient to self insert / being prescribed anti anxiety medication / going at a pace the patient is comfortable with. Some participants felt dehumanised and deindividualised when practitioners did not communicate with them or adapt the exam to their needs - "here we go again, here’s another vagina I gotta stick this damn thing in, open it up." One participant discussed feeling more pain with inexperienced practitioner as they were more anxious and tense. Health insurers only covering paps for people with a female gender marker reinforced that pap is only for women. Participants avoided screening if it wasn’t covered by health insurance or if it would only be covered following extensive self-advocacy. Also not being covered if gender marker is changed to M made patients feel resentment towards pap as an impediment to their transition and a reminder that healthcare doesn’t accommodate trans people. Some participants were forced to undergo paps to continue their transition, with some HCPs and health insurance companies saying they would not provide testosterone or hysterectomies if the patient did not attend screening. One transman reported that he attended screening due to fears of developing CC due to dysphoria from having the condition - "the idea of getting cervical cancer, would kill me as much as the disease might kill me". Discussions of gender dysphoria - "My dysphoria in general like increased by a million every time I had to have a Pap smear". Felt like they were back to being pretransition due to focus on feminine sexual anatomy. Feel vulnerable having people look at genitals as they are used to other people not knowing what genitals they have, but feel on show and exposed during screening. |
| Peitzmeier et al (2019) | USA | To explore how gender and power dynamic between provider and participants affect experiences of CCS among TMNB. | 32 transmasculine patients and 17 providers recruited from Fenway Health, a LGBT specialist health service in Boston, Massachusetts, USA. | Qualitative study using a modified grounded theory approach to analyse patient interview and provider interview and focus group data. Thematic analysis of verbatim transcribed interviews. | Effort taken to include diverse group of patients, such as older trans patients and trans patients of colour by slowing recruitment - not including people on first come first serve basis to allow more time to reach harder to reach groups. Participants taken from trans specialist health service | Patients and providers enact power during procedure - processes can either reinforce or challenge the power imbalance. Trans people have a more positive experience when they work to challenge the power imbalance, e.g.// by affirming patient choice, mitigating vulnerability and making modifications to the procedure to minimise discomfort, and patients self advocacy. Provider and trans patient also affirm or disaffirm gender identity, called constructing identity. More comfortable when using correct terminology, degendering the procedure, and normalising transgender bodies. Balance of power should be shifted to patient to construct and affirm their gender. Perceived force to undergo ccs in order to receive testosterone therapy as traumatising and invasive. Patients reported that providers ignored their calls for the exam to stop due to pain, which they described as an extreme violation, dehumanising, and likened to rape. More comfortable when able to bring a trusted friend, able to self insert, and able for the procedure to happen in a different position e.g.// without stirrups. Felt uncomfortable when providers referenced their body in non medical ways e.g. "manly looking legs" or referencing tattoos or genital piercings as they felt on display, scrutinised and judged. Felt dehumanised if it was performed in a transactional or perfunctory manner - "just another vagina". Self advocacy allows patients to resist disempowerment and disaffirmation of gender by stating needs and refusing unaffirming care. One participant said he had gotten more confident during transition and now feels able to self advocate for affirming care. One participant with a history of abuse requires being told every step rather than procedure just happening and has difficulties in telling them to stop, so prefers the provider to ask at each step if its okay to continue. Several patients prefer being asked what terminology to use to refer to their anatomy as they prefer not to use gendered terms as to differentiate their bodies from cisgender women. Prefer different words as hormones etc change how body looks - "I don’t actually have a traditionally female body anymore, so why should you treat it that way?". Feels "out of place" to be in waiting rooms for CCS as they are full of women, would prefer a gender neutral environment. Felt more comfortable when able to reaffirm screening as gender neutral or masculine, e.g.// viewing it as a necessity for health care or using metaphors for looking after machines. |
| Potter (2015) | USA | Narrative review to create guidelines for screening trans+ people for clinicians. | 118 trans patients involved in either an interview (32) or questionnaire (86) and 17 health providers. | Narrative review and 32 one-on-one, in-depth interviews and an online survey (n=86) with individuals on the FTM spectrum as well as three focus groups with 17 primary care physicians, gynaecologists, physician assistants, and nurse practitioners. | Little information on characteristics of sample, and on the methods used. | Many FTM patients face barriers to receiving needed services due to a combination of factors, including stigma and discrimination, lack of insurance and access to gender- affirmative health care, patient and health care provider misperceptions pertaining to HPV and cervical cancer risk and apprehension about undergoing intrusive procedures such as pelvic examinations. Social stressors such as experiences of discrimination in the health care system (enacted stigma) lead to the expectation of negative experiences in health care (anticipated stigma). Expectations of poor care may delay routine preventive care such as cervical cancer screening. It is imperative that cross-gender hormone therapy not be withheld or postponed because a patient on the FTM spectrum is not up to date with a Pap, just as one would not withhold needed services from a cisgender woman in this situation. Improving access to care begins before a transgender patient enters the office - inclusive policy docs, indicators of being trans friendly. Discomfort with waiting in a room full of cisgender women as a masculine- presenting individual. This effect is magnified if the patient’s (still female-gendered) legal name is used in the waiting room and people express confusion when the (masculine- presenting) patient responds. Finally, an FTM patient’s sense of safety can be threatened if the practice offers only gendered restrooms where their gender may be explicitly challenged. the Pap test should be presented as a non-gendered cancer screening procedure rather than a screen for cancer of female reproductive organs. Useful questions include: “Have you had a pelvic examination/Pap test before? ”Would you like me to explain the details of the procedure? ”How have your past experiences gone? ”Is there anything that would make you more comfortable?” The provider can then provide tailored information about the exam, ascertain patient preferences regarding provider gender and chaperone, and review options that may facilitate emotional and physical comfort. Since minor bleeding is common after cytology sampling, but can be an unpleasant reminder of menstruation or prior trauma for some patients, mention and normalize this possibility using non-gendered language. |
| Roznovjak (2023) | USA | Understand trans peoples perceptions of developing cancer, and of screening guidelines, and whether they would stop hormones if it was likely to lead to cancer. | 86 participants: 43% TG men, 24% TG women, 20% NB, and 13% who identified as other. 86% non-Hispanic white. | Survey at one institution, an LGBTQ+ health clinic. | Only from one LGBTQ+ health clinic - doesn’t represent experiences of those who are not connected with LGBTQ+ specific services. | Only 51% of those eligible had undergone cervical screening in the past 5 years. Provider and patient edu- cation on cervical cancer screening for TGNB persons is urgently needed. Gender dysphoria and health care anxiety were the primary reasons they had not undergone cervical cancer screening |
| Seay et al (2017) | USA | Aim to explore experiences of and preferences for cervical cancer screening among transgender men | 91 transgender men aged 21-63 who had not undergone a hysterectomy. Recruited participants from community events in south Florida | Community-based participatory research (CBPR) approach meaning that community members were involved in all steps of research. Conducted surveys with questions about experience of and preferences for cervical cancer screening. Some surveys were conducted in person at community events in south Florida, and others completed it online in other parts of US. Data analysed using SPSS. | Community members involved in all stages of research. | Uptake of cervical cancer screening is likely to be lower among TM who are not connected with LGBT competent providers. 6.6% reported that they would refuse both cervical cancer screening and hrHPV self testing. Some participants did not attend screening due to anticipated discrimination and others did not attend due to cost and not having health insurance. Participants were more likely to prefer hrHPV self sampling. Participants who had attended pap smears were more likely to want to continue with this method. Previous negative experience of healthcare, such as discrimination or not being able to afford it, may deter participants from engaging with any type of screening including hrHPV self swabbing. |
| Semelyen (2016) | UK | Aim to explore barriers and facilitators of ccs among transgender men | 7 participants in London and Manchester recruited through trans organisations. | A conference abstract discussing results of qualitative research on CCS among transgender men. Conducted interviews and focus groups which were transcribed verbatim and thematically analysed | Conference abstract. 7 participants recruited through trans organisations, some trans people may not be connected with them. | Social and peer support was important to motivate transgender men to seek pap smears. HCP acceptance of gender identity was crucial when deciding whether or not to attend screening. Participants had understanding of need to be screened for health, but were put off by past negative pap and general health care experiences. Respect and sensitivity is important for positive experiences in CCS. |
| Shires (2019) | USA | To examine the willingness of attending physicians, advanced practitioners, and residents to provide cervical cancer screening to trans and nonbinary people and the factors associated with this | 60 health care professionals in the Women’s Health department of a US health service recruited via the email service | A survey which assessed provider willingness to screen trans and nonbinary people, as well as various factors related to this such as levels of empathy or transphobia. | 74% response rate - may skew results to be more positive as transphobic people / those who don’t care about trans health may not have responded due to this. Also recognise it could be because of business of HCP work. Did not ask about gender diverse/nonbinary people so may only show for trans men. | Experienced difficulty finding culturally competent providers. 85% of attending physicians, advanced practitioners, and residents in the Women’s Health department of a health service in the USA reported willingness to screen transmasculine people. 40% had cared for a trans person in the past 5 years. Political opinions significantly affected willingness of providing pap smears - 86.7% of liberals, 100% of moderates, 44% of conservatives, only 9/60 participants identified with conservative politics. Higher empathy scores for participants willing to provide routine care and pap smears. Lower transphobia scores for participants willing to provide routine care/ccs. Political opinions, personal contact with transgender population and transphobia are associated with willingness to provide both routine care and ccs. Most providers willing but too many are not. Clinical contact with transgender people, training and knowledge barriers were not associated with unwillingness; more important to tackle transphobia than knowledge as bias and beliefs affect willingness more. Expansion of scope for providers to provide better care for trans population would not compromise care for cisgender women. Methods to improve could include use of gender affirming language, provider advocacy for trans health, demonstrating empathy and creating trans-specific policies. |

## Appendix 5 – Social media recruitment flyer

Caption for the image: Call for participants to be involved in a project on trans and non-binary peoples experiences of cervical cancer screening in the North of England. Please click this link <https://transscreeningproject.wordpress.com/> for more information on what this may involve and to express your interest. Feel free to contact me via DM or email ([ggreaves2@sheffield.ac.uk](mailto:ggreaves2@sheffield.ac.uk)) to ask any questions. Thank you!

Text

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## Appendix 6 – Information sheet

**Information sheet for participants – V2 29-10-22**

*You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and take time to decide whether you wish to take part. If you have further questions feel free to contact me using the details at the end of this sheet.*

**Research project title: Trans and non-binary peoples’ experiences of accessing and attending cervical cancer screening in the North of England.**

This project aims to address trans men and non-binary peoples’ experiences of cervical cancer screening in the north of England. This includes all people who were assigned female at birth but have a different gender, such as male, non-binary, genderqueer, agender etc. Trans and non-binary people have a lower uptake of cervical cancer screening than cisgender women, and report more negative experiences. This project aims to explore reasons for this and how screening can be improved by looking at past experiences of cervical screening to see how negative aspects can be reduced and positive changes can be used more widely. This project has obtained ethical approval from the University of Sheffield.

**Why have I been invited to participate?**

You have been invited to participate in this project because I am recruiting trans men and non-binary people who live in the North of England to discuss their experiences of cervical cancer screening. This also includes people living in the North who travel to other areas for cervical screening, such as trans-specific clinics in the South of England. I am interested in getting a diverse group of participants, including people of colour, disabled people and older people to see if personal characteristics also affect experiences of cervical screening.

**Do I have to take part?**

No, it is up to you whether you decide to take part. If you do decide to take part, but later change your mind, you will be able to withdraw up to four weeks following the interview/ focus group without giving a reason. Please be reassured that your data will be anonymised by then which means you will not be identifiable by name or any other potential identifying characteristic.

**What would taking part involve?**

You will be given the choice of participating in either an interview or an online focus group.

|  |  |
| --- | --- |
| **Interview** | **Asynchronous online focus group** |
| If you decide you would like to participate in an interview, you will be invited for an interview that will last around an hour to discuss your experiences of cervical cancer screening. This may include what happened during the procedure, your thoughts and feelings before during and after, or why you avoid cervical screening. This will take place over google meet or by telephone and will be arranged at a time convenient to you. The interview will be recorded and transcribed and used within the research to allow us to understand experiences of cervical cancer screening and how these can be improved. Your interview will be anonymised through the use of pseudonym, which you can either choose or be given. | If you decide you would like to participate in a focus group, you will be invited to join a page, similar to a forum, where you will be able to respond to questions posed by the researcher, along with other participants. This will be anonymous: you will not know the names of other participants and they will not know yours. You will be given two weeks to respond to the prompts before the page is closed. The page will be made on Wordpress.com and will be password protected so other people outside of the participants and researchers cannot see your answers. The responses will be downloaded into a transcript and used within the research to allow us to understand experiences of cervical cancer screening and how these can be improved. Any potentially identifiable information will be removed, and you will use a pseudonym that you either choose or are given. |

**What are the risks and benefits of taking part?**

Whilst there are no immediate benefits for those participating in the project, it is hoped that this work will help to improve cervical cancer screening experiences for patients in the future. However, this topic is sensitive and can be difficult to talk about so you may feel uncomfortable with some topics discussed within the interview or online focus group. You will be given the option to refuse to answer or discuss any questions or topics and will be given breaks during data collection if needed. You will also be able to rearrange the interview if you become too uncomfortable, or withdraw from the study without giving any reasons.

**How will my data be used?**

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team: myself and my two supervisors. Transcripts of your data will be stored on the University of Sheffield’s X:drive where it will be safe and secure and will be stored using a pseudonym of your choice, with any identifiable data such as your location removed. You will not be able to be identified in any reports or publications. As per our ethics guideline, confidentiality will only be broken if you disclose that yourself or someone else are at an immediate risk of harm, and the appropriate steps following this will be discussed with you.

**Reporting concerns or making a complaint**

Minimising harm to all participants is a key priority in this research project. Therefore, if you wish to raise any complaints, or to report an incident or concern, you can either report them to me, to my supervisory team (contact details below), or to the Dean of the Health Sciences School at the University.

*If you wish to make a report of a concern or incident relating to potential exploitation, abuse or harm resulting from your involvement in this project, please contact the project’s Designated Safeguarding Contact (Prof Tracey Moore;*[*tracey.moore@sheffield.ac.uk*](http://tracey.moore@sheffield.ac.uk/)*). If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the University’s Research Ethics & Integrity Manager (Lindsay Unwin;*[*l.v.unwin@sheffield.ac.uk*](http://l.v.unwin@sheffield.ac.uk/)*).*

**Contact details**

**For more information about the project, please contact**

**Georgia Greaves**, PhD student, Nursing and Midwifery, Barber House Annexe, Clarkehouse Road, S10 2LA, [ggreaves2@sheffield.ac.uk](mailto:ggreaves2@sheffield.ac.uk)

**For complaints, or to report an incident or concern, please contact any of the following individuals:**

**Dr Sharron Hinchliff (supervisor),** Nursing and Midwifery, Barber House Annexe, Clarkehouse Road, S10 2LA, [s.hinchliff@sheffield.ac.uk](mailto:s.hinchliff@sheffield.ac.uk)

**Dr Jill Thompson (supervisor),** Nursing and Midwifery, Barber House Annexe, Clarkehouse Road, S10 2LA, [jill.thompson@sheffield.ac.uk](mailto:jill.thompson@sheffield.ac.uk)

**Professor Tracey Moore,** Dean of the Health Sciences School, Barber House Annexe, Clarkehouse Road, S10 2LA, [tracey.moore@sheffield.ac.uk](mailto:tracey.moore@sheffield.ac.uk)

## Appendix 7 – Interview Guide

Interview guide

* Introduce myself and the project
* Ask if they have any questions before we continue, and check they still want to continue
* Ask if I can begin the recording

Questions and prompts

* Why did you decide to be in the project and where did you hear about it?
* Tell me what you know about cervical cancer screening?
  + What does it look for / what does it involve / what happens after?
  + Where did you learn this?
  + Have you spoken about this with other people?
* Have you been invited for screening?
  + Who did you talk to about screening? Receptionist, GP, friend – cis/trans?
* Have you attended screening?
  + What made you choose to attend/not attend?
  + How did you feel before/during/after the appointment?
  + How have your experiences made you feel about reattending?
  + What were the health professionals like?
* What, if anything, do you think could’ve improved your experience?
* Share some of the modifications currently outlined in the research and ask whether they would find it useful/if there are others they can think of
  + Self-insertion or using a smaller speculum
  + Having a trusted friend
  + Explaining what will happen beforehand and asking at each step before continuing – trauma informed care

Ask if they have anything else to share, thank them for participating and end the recording.

## Appendix 8 – Screenshot of the focus group

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## Appendix 9 – Details from the welcome page

**Welcome to the focus group!**

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Welcome to the project! Thank you for agreeing to take part.

[Click here to access the focus group!](https://transscreeningproject.wpcomstaging.com/forum-2/)

The focus group will be open for two weeks. The questions in week one will ask about your experiences of screening, and in week two I will share changes suggested by previous research to improve screening and ask your opinions on these, as well as to ask any other things you think could improve screening.

Before you move onto posting: I want this to be a safe space for everyone to share their experiences and thoughts, so here are the ground rules:

* Feel free to write as much or as little as you like, but please write something in both week one (30th Jan – 5th Feb) and week two (6th -12th Feb)
* Please post when you feel comfortable and able to. If there is a question you do not want to answer, feel free to ignore this and move to the next.
* I will be replying to your comments to ask further questions when necessary so please check back to see if there are any more questions.
* Please feel free to ask questions and respond to other peoples posts. I would like for this to be a discussion with lots of different perspectives, so I encourage asking other people any questions you may have, or updating your own responses if you think of anything extra.
* Please don’t share identifiable information about yourselves! This can include your real name, your location or your social media. This is to protect your own privacy and anonymity.
* Also do not share the stories or posts that are written with anyone outside of the project in order to protect other peoples privacy.
* Please be kind and respectful of other peoples thoughts and experiences. If people are unkind to other participants in the project, I will delete the comments and if this repeats I may remove the participant.
* I will be monitoring the form throughout the 2 weeks it is open for, and when it ends I will be downloading the posts as a transcript to be included in the research project.
* And of course, if you decide you no longer want to take part, feel free to withdraw at any time.

Feel free to contact me at any time if you have any questions or concerns. And thanks again for being involved in the project!

## Appendix 10 – Codebook

| Name | Description |
| --- | --- |
| Assumptions | Assumptions made by HCPS about trans/LGBTQ+ people and bodies |
| Avoidance | Avoiding attending cervical screening, including skipping regular screening and delaying appointments |
| Blaming themselves | Participants blaming themselves for finding screening difficult or for having unsuccessful screenings |
| Body image | Issues trans+ participants have about their bodies, outside of gender dysphoria, and other people seeing them |
| Choosing whether or not to go | How participants came to decide whether to attend screening or not. |
| Health maintenance | Attending screening for the health benefits |
| Coming out to hcps | Experiences of coming out to health professionals, including coming to the decision to come out or not |
| Control | Feelings of being in or out of control during the screening procedure |
| Dread | Dreading attending screening appointments |
| Dysphoria | Gender dysphoria – distress which comes from the incongruence between a persons gender and their body |
| Embarrassment | Feeling embarrassed about certain aspects of screening |
| Feeling affirmed | Having their gender affirmed – i.e. feeling recognised and respected in their gender |
| Feeling uncomfortable | Feeling uncomfortable around cervical screening |
| Feelings afterwards | How the participants feel after attending screening |
| Feelings of uncertainty | Feeling uncertain |
| Frustration with system | Feelings of frustration with how the screening system/ health system is set up |
| Gendered environment | Issues that arise with the environment, including social environment, being gendered |
| Get it done | Participants feeling like they need to attend screening and “get it done” |
| Good things | Good aspects of screening including experiences and things that could be improvements that do not fit into other categories |
| Ignored by health systems | Feeling like trans people are ignored by health systems/services |
| Improvements | Things that could improve screening experiences |
| Choice | Being given more choice around screening practices |
| Degendering | Making screening more gender neutral and less geared towards women, i.e. the environment or the words used around screening |
| Distractions | Distracting yourself from the procedure as it happens |
| Doing something affirming | Doing something gender affirming – that recognises and respects gender identity and helps to ease gender dysphoria – either before, during or after the procedure. |
| Dressing affirming | Wearing gender affirming clothes to the screening procedure |
| Educating hcps | Issues to educate health care professionals around in relation to being trans, trans health or providing cervical screening to trans people |
| Feedback | Health services responding to and acting on feedback given by trans patients |
| Mental preparation | Ways in which participants mentally prepared themselves before screening |
| Pillow under hips | Having a pillow under your hips during the procedure to reduce physical pain |
| Queers helping queers | LGBTQ+ people feeling the need to help other LGBTQ+ people, mostly in response to feeling like no one else will do it. |
| Reassuring hcps | Health professionals who behave kindly and in a reassuring manner when patients are struggling during the procedure. |
| Self insertion | Inserting the speculum yourself |
| Smaller speculum | Being given the option of using a smaller speculum |
| System changes | Changes to the system to improve trans peoples experiences of screening, including the physical system such as invitation system, as well as how the screening procedure is undertaken. |
| Talk through step | The health professional talking the patient through each step and asking for consent before continuing |
| Trauma informed | The health professional being aware that certain trauma may impact a patients experience and knowing how to provide care to people with trauma |
| Trusted friend | Taking a friend into the screening appointment with you |
| Inclusive docs | Having trans-inclusive documents, such as policy or posters in the waiting room |
| Inconvenience | Aspects of cervical screening which are inconvenient – and the building up of lots of little slightly inconvenient things that make it unbearable |
| Indicators of queer friendly | Having things to show that the practice is queer friendly – rainbow badges or pins or asking for pronouns |
| Intersectionality | The impact of having multiple marginalised characteristics on screening experiences |
| Autism | The impact that being autistic and trans has on screening experiences |
| City vs rural | The impact that living in a rural area or a city has on screening experiences |
| Disability | The impact that being disabled and trans has on screening experiences |
| Knowing people w cc | Knowing other people who have had cervical cancer and the impact of this on attending screening |
| Knowledge of screening | The knowledge that a person has about screening & its importance |
| Lack of info on trans ccs | A person having limited information about screening for trans people and the limited information that exists about screening for trans people |
| Low expectations of HCPs | Participants having low expectations of health professionals i.e. in terms of their knowledge around trans people or of trauma informed care |
| Media influence | Issues relating to how trans+ people are spoken about in the media |
| Method | Participants reflections on the method used to undertake this project |
| Nervousness | Feeling nervous about screening |
| Non-binary specific | Issues relating to screening that only exist for non-binary people, and not binary trans people |
| Other gay experiences | Other experiences related to gender/sexuality outside of the health system that may impact health care experiences, including screening. |
| Other hcps | Experiences had with other health professionals outside of screening |
| Pain | Physical pain from screening |
| Past experiences | Past experiences of accessing or attending cervical screening and their impact on future reattendance. |
| Preparing for procedure | How participants prepare to attend their screening appointments |
| Pushed to go | Feeling pushed by other people to attend screening |
| Self advocacy | Advocating for yourself around needs relating to screening |
| Sexual trauma | Having past experiences of sexual violence which impact cervical screening experiences |
| Shame | Feeling shame about screening or other factors related to screening |
| Speaking with others | Conversations had with other people about cervical screening |
| The results | The results of cervical screening including the worry and relief felt whilst waiting for results or once the results have arrived |
| Transition | How various aspects of medical transition impact the screening procedure |
| Transphobia | Intentional or unintentional acts of discrimination towards a person due to their trans status |
| Trust in hcps | Whether or not a person feels able to trust health professionals and the impact of this on screening |
| Uncomfortable comments | Uncomfortable comments made about trans people or their bodies by health professionals during screening appointments |
| Unsuccessful screening | The health professionals being unable to get an adequate sample during the screening appointment |
| Disappointment | Feeling disappointed due to the screening procedure being unsuccessful |
| Wanting to get it over with | Wanting the screening procedure to go as quickly as possible to be over with |
| Worries | Worries relating to accessing or attending screening |

## Appendix 11 – Extract of annotated and coded transcript

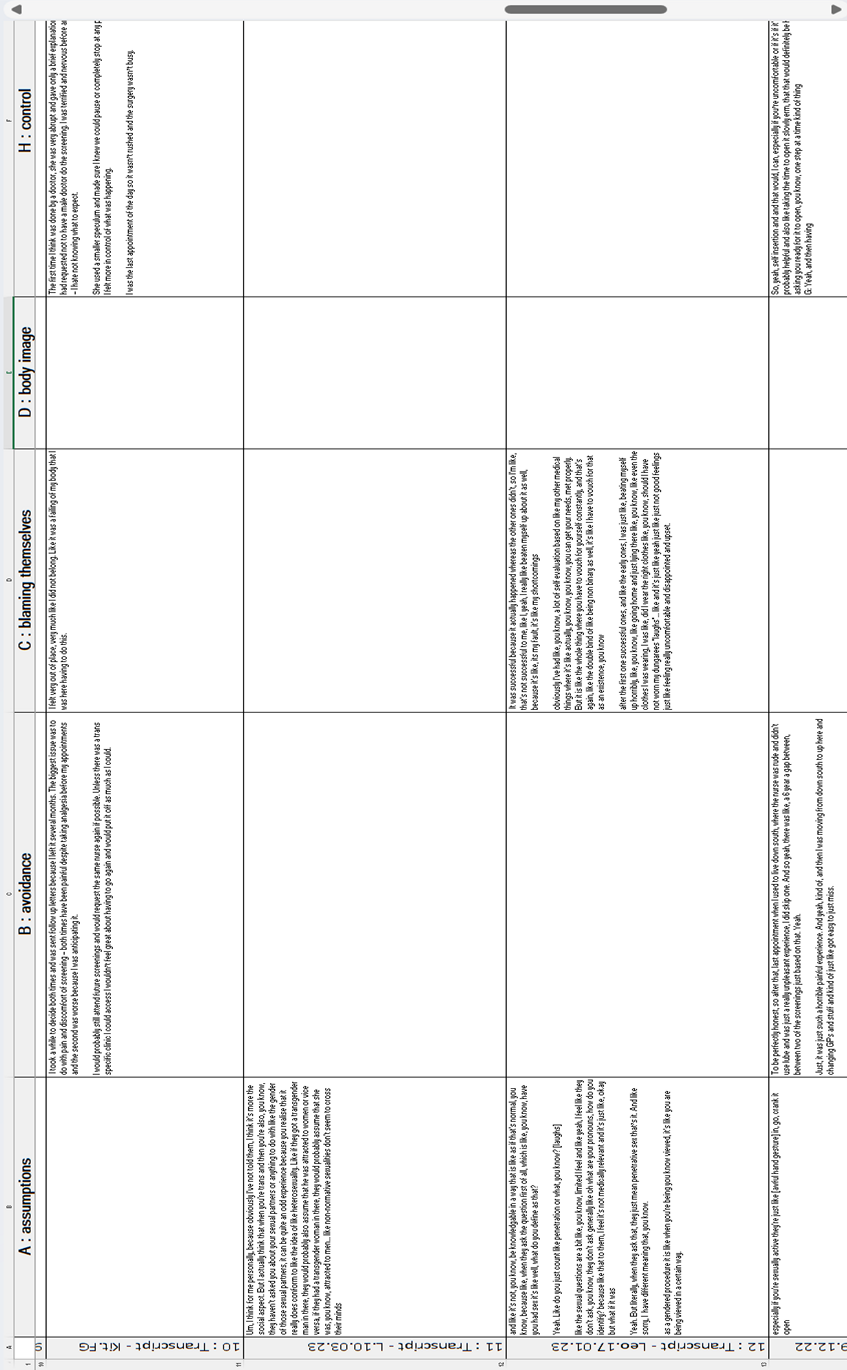
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## Appendix 12 – Extract from the Coding Matrix



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## Appendix 13 – Table of final themes

|  |  |  |
| --- | --- | --- |
| Theme | Subtheme | Transcript extract |
| Theme One – How do trans+ people decide whether to attend cervical screening? | Health Maintenance as a Motivator | Um, due to the fact that there’s breast, bowel and cervical cancer sort of in the family, I can’t, I can't afford to not go back - Ethan |
|  | “Trans people like me just get forgotten”: Feeling ignored by health systems | And, yeah, be nice to have a system that took medical system in general, that took trans health care, seriously, and, but obviously yeah that's a long way off. - Robin |
|  | Worries about attending cervical screening | It’d definitely be easier for me to attend if I’d had more positive experiences with receiving healthcare at my practice while I identified as cis and during the period I was non-binary but hadn’t disclosed it, and if they’d given even a little bit of care when I asked to change my name and start gender-related processes. - Jamie |
|  | “Oh yeah, I put it off for a good amount of time”: Avoidance or Delaying of Screening | I know that the screening is incredibly important to do, so I definitely intend to attend a screening at some point. Right now, I’m concerned about a lack of understanding around my gender dysphoria and discomfort around screening from whoever would be doing it, especially because I’d probably have to accept misgendering and dysphoria during a physically intense practice. I’m just not in the headspace for it right now. - Jamie |
| Theme Two – Screening is never “good” but what makes our experiences more positive or negative? | Considering experiences independently is not enough: the interaction of multiple factors | I've got to make an appointment with the GP, explain I need the referral, wait for the second letter from colposcopy to drop on the doorstep, arrange for my mum or a carer to accompany me, get stared at by all the women in maternity, even if they're not it's how I feel, and just go through all that, all that process, even if the screener is pretty positive, once I get into the room, it's all the issues around it. - Ethan |
|  | All participants were worried about pain: their experiences of physical pain and discomfort | Being on testosterone actually makes me incredibly dry in between my legs, so having speculum inserted can be even more painful and it can be quite difficult, trying to explain that to some doctors that are not sort of gender aware, so it it's great if you get somebody that says, oh I see you’re on testosterone, we can use some lubricants but that's very rarely the case. - Ethan |
|  | “It’s a very disempowering position to be in, isn’t it?”: Feelings of empowerment or disempowerment | Really weird way to describe it but a little bit violated in a way, just because it doesn't feel, I don't know, feels a bit weird, its really painful, its something I don’t want to do. Yeah. - Jack |
|  | The impact of gender dysphoria or gender affirmation on experiences of screening | I felt very out of place, very much like I did not belong. Like it was a failing of my body that I was here having to do this. - Kit |
|  | “It just made me feel like really out of control”: Reliving sexual trauma during cervical screening | It just made me feel like really out of control. Just like I had no say over what was gonna happen. Yeah. And especially for like, I'm speaking for myself here, but I'm sure it was the same for other people who've had like sexual assault experiences in the past, that can just feel a little bit like reliving it. - Jack |
|  | Our needs aren’t being met: disabled trans+ experiences of screening | Hospitals in general are a bit of a sensory overload ‘cos they're so bright and there's so many people, they've always got the TV on. And it's distracting and you can't like, put your headphones on because you miss people yelling at you… so I have to sit there with my headphones off, it just already awful. - Ryan |
|  | Health professionals: creating comfort or discomfort | A lot of factors had to “align” for this experience to have played out the way it did. I was in the right place mentally, the GP was considerate and experienced, and my gender identity for the sake of the procedure going well was (arguably) irrelevant. If I had experienced any untoward reaction because of my identity, I’m not sure I would have been able to relax, so the attitude of the GP was paramount in maintaining my calm. - Bruce |
| Theme three – Relief or regret: participants thoughts and experiences following screening appointments | Emotions experienced by participants following successful and unsuccessful screening appointments | Like with the determination that it could be done differently, Like, you know…I was like, it's offputting to go through all that kind of stuff, but then, at the same time, it's like erm… I was like, I'm the kind of person were in, like, if I've got kind of a barrier, I'm like, I want to get over that so I was like, well, how can I do like that then? I was like, I would go home and I would look stuff up again and be like, are there any resources for like LGBT people I don't know about and then like just keeping an eye out on that kind of stuff. - Leo |
|  | The impact of screening experiences on future reattendance | The very first time I went for one, it was it was quite traumatic, it wasn't, it wasn't done nicely so that, that put me off for a while. - Jocelyn |
| Making screening more manageable: recommendations for improving cervical screening for trans+ people | The importance of choice; potential modifications to the procedure | Using smaller speculums with more lubricant really really helps, due to the fact testosterone causes a lack of elasticity and dryness…We already used the smallest sized speculum available for my smear specifically because I’m a trans man, which definitely made the whole experience more comfortable - Andrew |
|  | Improving medical education and training | More awareness of why it might be more difficult, better understanding of queer health generally by clinicians…More training and awareness on why it might be difficult for trans/queer people too. - Kit |
|  | De-gendering cervical screening is good for everyone | Yeah, it's like I've had, I've had friends who've had miscarriages and they've kind of described the whole…you know, people said that have lost their child, which is an awful experience, they still get post through, they still get letters or invites or marketing stuff because no one's taking them off the right thing, whatever, and then that's very traumatizing for them, you know. So it's, it's yeah there's this kind of definitely stuff around yeah, it would help cis women a lot. - Ryan |
|  | The importance of community in coping with cervical screening | I think with other trans people there's definitely like the potential, you know, for like dysphoria around body parts and uncomfortable, you know, conversations to be had with healthcare providers erm… and potential for misgendering etc which introduces a sort of different nuance erm to those conversations that we might have and, you know, with like people that, you know, my cis friends, I might share that as well, but with less of a kind of mutual, understanding base, you know. - Dave |

## Appendix 14 – Ethics Approval Letter

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## Appendix 15 – Consent Form

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**Trans and non-binary peoples’ experiences of accessing and attending cervical cancer screening in the North of England Consent Form: V2 18-10-22**

Before participating in this project, you must read and understand the information sheet and sign this consent form.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| ***Please tick the appropriate boxes*** | | | **Yes** | **No** |
| **Taking Part in the Project** | | |  |  |
| I have read and understood the project information sheet dated 06-10-22 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.) | | |  |  |
| I have been given the opportunity to ask questions about the project. | | |  |  |
| I agree to take part in the project. I understand that taking part in the project will include taking part in either an interview or an online focus group which will be recorded and transcribed by the researcher. I have been given the choice of which I will be involved in. | | |  |  |
| I understand that my taking part is voluntary and that I can withdraw from the study up to four weeks after the interview or focus group; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw. | | |  |  |
| **How my information will be used during and after the project** | | |  |  |
| I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project. | | |  |  |
| I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be identified in these outputs. | | |  |  |
| **So that the information you provide can be used legally by the researchers** | | |  |  |
| I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield. | | |  |  |
|  |  |  | | | |
| Name of participant [printed] | Signature | Date | | | |
|  |  |  | | | |
| Name of Researcher [printed] | Signature | Date | | | |
|  |  |  | | | |

**Project contact details for further information:**

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Dr Jill Thompson (Supervisor), Department of Nursing and Midwifery, Barber House Annexe, 3a Clarkehouse Road S10 2LA Email: [jill.thompson@sheffield.ac.uk](mailto:jill.thompson@sheffield.ac.uk)

Professor Tracey Moore, Head of Division, Department of Nursing and Midwifery, Barber House Annexe, 3a Clarkehouse Road S10 2LA, Email: [tracey.moore@sheffield.ac.uk](mailto:tracey.moore@sheffield.ac.uk)

The template of this consent form has been approved by the University of Sheffield Research Ethics Committee and is available to view here:

<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage>

## Appendix 16 – Signposting sheet

**Support services**

**Arcus LGBT+ CIC**

Arcus is a national support service for LGBTQ+ people which offers counselling, a support line and well-being and mentoring. The service uses a sliding scale of cost and offers free sessions to those in need. The free support line is open everyday from 6pm-10pm

Website: <https://arcuslgbt.com/>

Support line: 01325 978 007

**Galop: The UK’s LGBT+ anti-abuse charity**

Galop is a national charity that has provided support for LGBTQ+ survivors of sexual and domestic abuse and hate crimes for over 30 years.

Email: advice@galop.org.uk

Website: <https://galop.org.uk/>

**Mindline Trans+**

Mindline Trans+ is an emotional and mental health support helpline run by trans people for trans people. It is open Monday, Wednesday and Fridays from 8pm-midnight.

Helpline: 0300 330 5468

Website: <https://mindlinetrans.org.uk/>

**Live Through This**

Live Through This is a cancer charity for LGBTQ+ people who have been affected by cancer. It offers support groups with other queer people affected by cancer as well as information related to cancer for LGBTQ+ people, including cervical screening.

Website: <https://livethroughthis.co.uk/>

1. Some trans identities fall within the gender binary, which refers to classifying individuals into two categories: man or woman (Vincent 2020). Binary-oriented trans identities are trans men, which refers to people assigned female at birth (AFAB) who identify as a man, and trans women; someone who was assigned male at birth (AMAB) and identifies as a woman (Stonewall 2017). Genders which go beyond the gender binary can be referred to under the umbrella term non-binary, which means they do not identify as male or female, such as agender, genderqueer or bigender (Stonewall 2017; Vincent 2020). [↑](#footnote-ref-1)
2. The term deadname refers to a name a trans+ person used before transitioning, such as their birth name, as opposed to their chosen name. [↑](#footnote-ref-2)
3. The term misgender means referring to a person as the wrong gender, such as using the wrong pronouns or gender labels. [↑](#footnote-ref-3)
4. A condition in which the muscles in the vagina suddenly tighten, causing pain, in response to physical contact, pressure, or penetration. [↑](#footnote-ref-4)
5. Some trans identities fall within the gender binary, which refers to classifying individuals into two categories: man or woman (Vincent, 2020). Binary- oriented trans identities are trans men, which refers to people assigned female at birth (AFAB) who identify as a man, and trans women; someone who was assigned male at birth (AMAB) and identifies as a woman (Stonewall, 2017). Genders which go beyond the gender binary can be referred to under the umbrella term non- binary, which means they do not identify as male or female, such as agender, genderqueer or bigender (Stonewall, 2017; Vincent, 2020). [↑](#footnote-ref-5)
6. TMNB are less likely to produce a sample that can be tested for HPV or abnormal cervical cells. For example, TMNB are more likely to bleed during CCS and too much blood in a sample renders it unusable. [↑](#footnote-ref-6)