The Emotional Impact of Testing Positive for High-Risk HPV: an Exploration of Cis-Women's Experiences Following a Positive Test Result in the UK.

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Abstract

Aims: High-risk HPV is often stigmatised and feminised. Testing positive for high-risk HPV is associated with a range of distressing emotional and relational responses. The aims of this study were to explore the emotional experience of cis-gender women testing positive for high-risk HPV in the UK. Specifically, it explored sense making and meaning making.

Method: Six semi-structured interviews were conducted with cis-gender women who had tested positive for, or were diagnosed with, high-risk HPV at routine cervical screening. The interviews were analysed using Interpretative Phenomenological Analysis.

Results: Four Group Experiential Themes were identified showing the extent of emotional and psychological distress associated with testing positive for high-risk HPV. Ten sub-themes were identified. These showed the impact of high-risk HPV at several levels from societal through to individual. The themes highlighted the impact of stigma and feminisation, emotional distress associated with interactions with NHS systems, and experiences of connection and disconnection. Finally, the themes highlighted this process as an emotional journey, and the impact on identity and control.

Implications: Findings of this study were discussed alongside relevant theory and literature with careful consideration of clinical implications. The implications suggested a need to consider language and narratives when high-risk HPV is discussed both within the NHS and wider services (e.g. schools), the impact of assigned female at birth only testing, the delivery of positive test results, and better integration of physical and mental health in relation to high-risk HPV.

Chapter 1: Introduction

This thesis researched the experience of cis-gender women who were diagnosed with or had tested positive for[1] high-risk Human Papillomavirus (hrHPV). This chapter discusses my positioning to the research and my epistemological stance. It then outlines some key terms and definitions, an understanding of hrHPV from feminist perspectives and the known psychosocial impact of testing positive for hrHPV. The systematic literature review (SLR) reviews the narratives, attitudes and beliefs about hrHPV held within the UK general population before outlining the rationale for the research.

My Position Within the Research

My positioning to this research was reflected in both my experiences, and narratives shared with me, of being a woman navigating women's health-related issues. Whilst objectively, many of these experiences might be linked to aspects of female biology, there are several examples of how healthcare has been positioned as something for women alone to be concerned with. For example, when considering pregnancy prevention, it is noted that most emotional and physical labour is placed on women despite the shared responsibility of conception (Davis, 2017; Kimport, 2018) and that this disproportionate responsibility is often perpetuated by clinicians and systems in healthcare settings. When considering cervical screening, even though hrHPV has been shown to be prevalent in sexually active men and is detected via several methods of identification (Dunne et al., 2006), there is currently

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[1] Women whom I interviewed often had different views when relating to HPV as either a diagnosis or a positive screening result based on what fit more accurately for their personal experience. For the purposes of this thesis, I will mostly use phrases related to testing positive as this was most of my participants preferences. However, I may still refer to diagnosis whilst discussing individual participants experiences as this is what felt most accurate for them during the interview.

no routine screening, and the HPV vaccine was originally only offered to women and girls.

My insider positioning as a recipient of women's health services has presented itself with both advantages and disadvantages. For example, when considering building rapport, I believe that this aspect of our shared identities helped to create a safe space for participants to be open and honest about their experiences (Bhopal, 2010). However, this also brought the challenge of separating my beliefs and understanding from that of participants when aspects of our identities differed, and this required reflection of implicit assumptions (Bhopal, 2010).

It is also important to note my identity as a cis-gender woman (e.g. assigned female sex at birth (AFAB)) and appreciate the inherent privilege of this aspect of my identity. Attending cervical screening can be particularly difficult for people who identify as Trans or Non-Binary due to the way gender is entwined with the experience, for example, 'gendered' waiting rooms, staff attitudes, or distress caused by gender incongruence (Dhillon, et al., 2020), not to mention admin errors leading to those with changed gender markers being excluded from invitation (Berner et al., 2021). Therefore, whilst this thesis was written from the perspective that women often face discrimination within healthcare, it also acknowledged privileges afforded to being cis-gender within women's healthcare.

Epistemological Stance

The research was conducted from a stance of critical realism. I adopted this stance as it assumes that the underlying structures of emotional responses, and diagnoses or positive test results for hrHPV are "real" constructs (Willig, 2013), but also allows for interpretation of experiences. Healthcare is usually researched from a stance more in line with a positivist or realist approach which suggests that we can find a true, definitive answer. Approaching this from a critical realist stance provided a rich, real-world understanding of the phenomenon, whilst remaining based in "reality." This lens has been noted to respond to the limitations presented by an entirely realist or constructivist epistemology and helped to marry together physical health with wider social discourses (Murray & Poland, 2006). In addition, it helped to connect theoretical research with clinical practice and policy (Alderson, 2021).

Conceptualising High-risk Human Papillomavirus

Defining High-risk Human Papillomavirus and Other Key Terms

Epidemiology of High-risk Human Papillomavirus. Human papillomaviruses are a group of common viruses found in humans, most of which do not cause any symptoms, with a minority linked to warts or cancer (National Health Service (NHS), 2022). These different strains are usually categorised as either high-risk or low-risk strains. Many people will encounter at least one strain of Human Papillomavirus with roughly 80% of the population contracting HPV throughout their lifetime (Scott-Wittenborn & Fakhry, 2022). hrHPV[2] is associated with an increased risk for cancer. The National Cancer Institute (NCI) (n.d.(a)) defines hrHPV as "A group of cancer-causing human papillomaviruses (HPV) that are transmitted sexually. These viruses infect the cells on the moist surfaces or inner lining of some organs and body cavities, such as the cervix, vagina, vulva, penis, anus, mouth, and throat." Low risk Human papillomavirus (lrHPV) is defined as "A group of sexually transmitted human papillomaviruses (HPV) that infect the cells on the moist surfaces or inner lining of some organs and body cavities, such as the cervix, vagina, vulva, penis, anus, mouth, and throat. Low-risk HPV infections can cause warts on or around the genitals, anus, mouth, and throat (NCI, n.d.(b)).

As stated above, it is reported that the main form of transmission for hrHPV is via direct skin-to-skin contact either sexual (NHS, 2022) or non-sexual (Petca et al., 2020) with it becoming increasingly accepted that non-sexual routes of transmission are possible. There is also evidence to suggest possible indirect transmission through fomites, such as shared personal items (NHS, 2022) or medical equipment

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[2] When referring to specific types of strains of HPV, I will refer to these as either hrHPV or lrHPV accordingly. When it is unclear which strain is being spoken about, for example in other research or by participants, I will refer to this simply as HPV throughout this thesis.

(Petca et al., 2020). Finally, there is also consideration of possible transmission from Mother to baby during pregnancy or birth (Petca et al., 2020). It is reported that the current most effective method of prevention against most strains of hrHPV and some lrHPV is vaccination (NHS, 2022), which is recommended for children aged 12 to 13 in the UK as it is most effective prior to exposure to hrHPV (Ellingson et al., 2023). Condoms can help to protect against hrHPV, but as hrHPV is transmitted through skin-to-skin contact this method is not entirely effective (NHS, 2022). Whilst hrHPV can be contracted the first time someone engages in sexual activity there is some evidence to suggest that those with a higher lifetime number of sexual partners might be at higher risk for contracting hrHPV (Baseman & Koutsky, 2005). However, it is important to emphasise that this is also influenced by the cumulative number of sexual partners between individuals who are engaging in sexual activity, and in younger girls a larger difference in age between the individual and their sexual partner (Baseman & Koutsky, 2005). Other risk factors for identified infections with hrHPV are reported to include those in younger age groups, younger age of first sexual activity, being single and smoking (Ferris et al., 2020) and for men, those who identify as gay, bisexual or otherwise engage in sexual activity with other men (NHS, 2023a). The NHS also suggests that those who identify as transgender might hold a similar risk as men who have sex with men (NHS, 2023a). They also suggest that those with compromised immune systems (such as those diagnosed with HIV) and sex workers to be at increased risk from hrHPV. When interpreting identified risk factors, It is also important to note that as hrHPV has often been highly linked to cervical cancer, most epidemiological study has been focussed on women (Baseman & Koutsky, 2005) and more recently men who have sex with men.

Most women who contract hrHPV will clear the infection within the first twelve to twenty-four months (Scott-Wittenborn & Fakhry, 2022), and therefore many women may contract hrHPV between cervical screening appointments or prior to commencement of screening without knowledge. However, 10-20% of women will present with persistent infection beyond this two-year period (Scott-Wittenborn & Fakhry, 2022). hrHPV can also become "latent," meaning that it can appear the virus has been cleared by the immune system when it has reduced to levels that are currently undetectable by current screening protocols, but the virus remains present in the body (Baseman & Koutsky, 2005). Over time, the persistent presence of hrHPV can lead to the development of abnormal cells in the body, which if left undetected and untreated can develop into cancer, however it is estimated that in most instances this process happens over a period of many years (Baseman & Koutsky, 2005).

As stated, HrHPV is mostly associated with Cervical Cancer, one of the most common cancers affecting individuals AFAB (Sung et al., 2021), despite its high prevalence in cancers specific to individuals assigned male sex at birth (AMAB) and those unrelated to assigned sex (Information Centre on HPV and Cancer, 2023). "Assigned sex" refers to how biological sex was identified at birth, based on genitalia (Stonewall, n.d.). Sex and gender can often be used interchangeably in research and academia (Muehlenhard & Peterson, 2011), which can introduce confusion, particularly in the context of gendered healthcare[3].

High risk Human papillomavirus from a feminist perspective*.* As referenced above, hrHPV is also categorised as a common sexually transmitted infection (STI) (Cancer Research UK, 2024), which as outlined by Daley et al, (2017) suggests the involvement of more than one individual in transmission. Despite this, only women, and people born with a cervix are invited to attend testing for hrHPV. Furthermore, whilst women and girls have been offered the HPV vaccination since 2008, the national roll-out of this vaccination for boys and men did not start until 2019 (UK Health Security Agency, 2023). In contrast, in the USA HPV vaccinations have been routinely recommended for women and girls since 2006, and for men and boys since 2009 (Daley et al., 2017). Similarly, testing for hr-HPV was routinely used for women in America years prior to national rollout in the UK (Dodd et al., 2014) with attitudes towards hrHPV testing internationally ranging from a 13-84% acceptance rate

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[3] I will refer to women or females to mean cis-gender women, whose gender identity matches that assigned at birth and men or male to mean cis-gender men whose gender identity matches that assigned at birth. I will refer to women, and people born with a cervix when encompassing people who were AFAB but whose gender identity does not match this description. If it is unclear whether the identity of someone discussed matches their assigned sex at birth (e.g. in other research) I will use the language used by the person or the researcher.

(Nothacker et al., 2022). This earlier recognition of the impact of hrHPV in the USA has perhaps contributed to people In America having a higher level of familiarity and knowledge than in the UK (Dodd et al., 2014) but does not stop the resulting association between hrHPV and women permeating all levels within society and health services (Daley et al., 2017).

Thompson (2010) highlighted that despite awareness of: the role of men and women in transmission, the prevalence of lrHPV-related genital warts in both men and women, and some knowledge of the impact of hrHPV for men's health, the focus of hrHPV in both the USA and the UK remained concentrated on women. Consequently, this association between hrHPV and women's bodies worked to reinforce ideas that women are more responsible for sexual health in heterosexual relationships, and additionally placed the sole responsibility of prevention and treatment on women (Daley et al., 2017). Furthermore, Bunting (1996) described the disparity between "promiscuity" being more acceptable for men than women, further emphasising a need to assess and treat women for infections associated with undesirable behaviour.

This disparity is not unique to hrHPV and can also be seen in interventions like hormonal contraceptives (Davis, 2017). In addition, early condom advertisements were judged to be marketed more towards women, despite them not being the direct user, and noted to be less able from a power perspective to encourage the use in a heterosexual relationship (Higgins, 2007). The cumulative effect of these inequalities is therefore theorised to have contributed to the feminisation of hrHPV and a larger impact experienced by women and people born with a cervix, understood to be a way for women's bodies to be inspected and controlled (Daley et al., 2017; Thompson, 2010). This in turn has potentially encouraged men to take passive responsibility for sexual health (Thompson, 2010) and disempowered their knowledge and health-related decisions (Allen et al., 2009; McPartland et al., 2005).

Psychosocial Impacts Associated with hrHPV

Research supports the theory of additional burden, in terms of both adverse psychological and emotional impacts for women who test positive for hrHPV. Studies suggest testing positive causes short and long-term symptoms of anxiety and psychological distress (Jentschke et al., 2020; Kwan et al., 2011; McBride et al., 2020), has links to disgust and shame, and fear of developing Cancer (McBride, Tatar et al., 2021). Furthermore, women reported significantly more instances of guilt or stigma than men (Daley et al., 2015). Whilst some studies have suggested that the associated anxiety is only short-term, there is also evidence to suggest that nearly a quarter of women experience clinically significant levels of distress (McBride et al., 2020).

A recent SLR suggested a variety of psychological and emotional responses ranging from disgust and shame, surprise and confusion, sadness, relief or acceptance, and apathy (McBride, Tatar et al., 2021). This review drew on cognitive behavioural theory to understand the experience of testing positive for hrHPV, categorising the emotional responses as either negative, or neutral or positive, with the most common emotions to be anxiety and distress. They understood this to produce responses in terms of either negative behaviours such as impacting relationships, leading to non-disclosures and changes in sexual behaviour, or neutral or positive behaviours like seeking social support or future screening attendance. These behaviours were linked to either negative cognitions associated with low perceived control, confusion, cancer concerns, or neutral or positive cognitions, linked to high perceived control, trust in others, and acceptance. Whilst this SLR provided a helpful overview of the possible emotional processes, it provided an overview of the average experience, without attending to nuance. It also located the response entirely in the individual, without considering the impact of external contexts. Attempts have also been made using this framework to understand different responses in terms of either high or low anxiety, with some overlapping experiences such as disclosure, embarrassment or shame, and questions about the virus (McBride, Marlow, et al., 2021). Furthermore, whilst low levels of anxiety were also linked to emotions such as relief, not all the associated responses were necessarily positive. For example, women with low anxiety were also reluctant to disclose hrHPV due to associated stigma. This suggested that not all negative experiences can be attributed to high levels of anxiety alone (McBride, Marlow, et al., 2021). Whilst there are apparent differences in experiences of anxiety, it is important to highlight the impact of testing in the context of previous mental health difficulties with research suggesting a vulnerability to negative emotional responses (O'Donnell et al., 2024). This emphasised the potential role for clinical psychology in further exploration.

The impact of sexual transmission and stigma have also been linked to negative emotional responses (Perrin et al., 2006; Jo's Cervical Cancer Trust, 2022; Waller et al., 2005). For example, when reviewing newspaper narratives, one research study highlighted frequent mention of HPV vaccination and increasing adolescent sexual behaviour (Forster et al., 2010) despite no scientific link between these factors (Dreweke, 2019). Furthermore, rates of sexual behaviour and number of sexual partners are often cited as risk factors for contracting hrHPV (Pourmohsen et al., 2018), and whilst sexual transmission is known, it is often forgotten that infection can result from only one sexual partner. These narratives are perhaps then interpreted as hrHPV as a sign of sexual risk-taking, or unsafe sex practices.

Many women also talked about stigma, specifically in relation to responses from others (Bennett et al., 2020). This is consistent with previous definitions of stigma which suggest that this is due to an aspect of someone's identity becoming discredited, leading to potential social exclusion (Goffman, 1963). The impact of this stigma is suggested to have left women concerned about sharing the result with others and wondering when and with who the information should be shared (Bennett et al., 2020). This is perhaps consistent with theories relating to experiences of shame within health-related stigma which suggest that an individual might live in a state of chronic anticipation of being shamed by others or of feeling shame (Dolezal, 2022). Furthermore, research also suggests that higher levels of shame are experienced by those aware of hrHPV's sexual transmission, further emphasising the link between shame and stigma in negative emotional responses to hrHPV (Waller et al., 2007).

Whilst the studies and theories cited above attempt to understand this experience using a variety of models and frameworks, there is potential for further understanding to be developed from a phenomenological perspective. More specifically, much of the research described above was completed prior to the national roll-out of hrHPV primary testing (Albrow et al., 2012) and despite attempts to mitigate against the potentially harmful outcomes, this experience is still reported to be distressing. There are also clinically significant impacts to mental health, both sexual and emotional relationships, and possible additional burden to NHS services, further emphasising the need to develop this greater, more in-depth understanding.

Systematic Literature Review

The objective of the systematic literature review (SLR) was to synthesise ideas (Boland et al., 2017) on the context for which women might receive a positive test result or diagnosis of hrHPV in the UK. It aimed to use transparent and reproducible methods, including all published papers on the topic, whilst also critically appraising the quality (Lame, 2019). This method is considered more scientifically rigorous than traditional narrative reviews as the authors can be held accountable for the research they chose to privilege, due to the transparent nature (Dixon-Woods, 2010). The review aimed to explore views/perceptions of the general population on hrHPV. The objective was to provide a better understanding of the social context within which women may make decisions about HPV-related behaviours e.g. prevention, treatment, screening. As stated above, despite attempts to mitigate against the potentially harmful outcomes of testing positive for hrHPV, this experience can still be distressing, with clinically significant impacts to mental health, and sexual or emotional relationships, which therefore potentially places undue burden on the individual, and NHS psychological services.

The systematic literature review is reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines

(Page et al., 2021) and was also registered with the International Prospective Register of Systematic Reviews (PROSPERO; CRD42024550518).

Method

Search Strategy. I used the SPIDER tool (Cooke et al., 2012) to help focus my SLR (see Table 1), and this changed following scoping reviews and discussion with my supervisory team, consisting of Dr Emma Karwatzki (primary supervisor), and Dr Anna Bailey (secondary supervisor). For example, my initial scoping review showed a recent SLR (McBride, Tatar et al., 2021) exploring the emotional responses following a positive test result for hrHPV at cervical screening in several countries, with research published up until November 2019. As this review was conducted recently, it was decided to widen the scope to understand the perceptions of HPV within the general population in the UK. Whilst there is no strict guidance as to when a systematic review should be repeated, there was not substantial evidence that inclusion of the few, newly published papers would drastically alter these conclusions (Bhide & Acharya, 2015).

A search for papers on attitudes within UK general population showed that most research studied HPV in conjunction with vaccination or cervical screening. Therefore, it was decided to include papers with a substantial amount of data reviewing attitudes and assumptions towards HPV, even if researched alongside ideas about screening or vaccination.

Table 1: Overview of search strategy using the SPIDER tool

Sample	UK general population, of all ages, sexes or genders
Phenomenon of Interest	The Human Papillomavirus (HPV)
Design	Interviews or questionnaires and surveys.
Evaluation	Assumptions, attitudes, perceptions, ideas or narratives
Research type	Qualitative or mixed-methods design.

Key Terms. The Key terms shown in Table 2 were informed by the scoping review, a recent SLR (McBride, Tatar et al., 2021) and consultation with my supervisory team and the University Librarian.

For my search, I combined terms three and four with OR rather than AND as I was open to exploring the key terms related to narratives or attitudes. Although these concepts differ slightly, they both relate to the way in which things are perceived and understood and this search strategy ensured we captured papers researching these ideas from both perspectives.

Table 2: The search terms used for the SLR

Term 1	Term 2	Term 3	Term 4	Term 5
“High-risk HPV” OR “High-risk Human Papillomavirus” OR “High risk HPV” OR “High risk Human Papillomavirus” OR HPV OR “Human Papillomavirus”	Diagnos* OR "test* positive" OR "positive test result*" OR Abnormal* OR "Positive screen*" OR infect* OR positiv*	narrativ* OR discours* OR stor* OR comment*	belie* OR attitude* OR understand* OR idea* OR thought* OR think* OR expect* OR assum* OR presum* OR comprehen* OR percepti* OR view*	"Great Britain" OR UK OR “United Kingdom" OR "National Health Service" OR NHS OR Brit* OR Engl* OR Scot* OR Wales OR Welsh OR “Northern Ireland" OR Irish

Inclusion and Exclusion Criteria. All studies or grey literature focussed on developing a rich understanding of narratives or attitudes towards HPV as a virus, diagnosis, or test result in the general population which were available in English, conducted in the UK and published after the year 2000 were considered for the SLR.

Typically, research conducted using quantitative methods is underpinned by positivist principles that we can uncover a single “truth” and that this exists regardless of interpretation (Sale et al., 2002). As the focus of my literature review was to understand attitudes and narratives, both of which are influenced by the way a person perceives reality (Putnam, 1981), it follows that limiting my search to only qualitative papers provided an in-depth understanding of several interpretations of reality. In addition, during the initial scoping review many quantitative papers seemed to be more focussed on assessing a level of factual knowledge in line with the current scientific evidence at point of research (Knight & Roberts, 2021; Sherman & Nailer, 2018; Waller at al., 2003), rather than an in-depth exploration of how this influenced perceptions of hrHPV. It is for this reason that we chose to exclude studies using purely quantitative methodologies but decided to include mixed-methods studies with enough focus on developing this deeper understanding.

A cut-off point of the year 2000 was chosen to coincide with the introduction of hrHPV testing in the UK in early 2001 as part of three initial pilot studies (Moss et al., 2003), followed by the introduction of additional testing for a subset of women which was rolled-out by 2008 (Albrow et al., 2012) before later moving to hrHPV primary testing. Therefore prior to the year 2000 it is unlikely that members of the general population would be aware of HPV. Furthermore, a SLR exploring public opinions needed to include recent research to accurately reflect this.

I included both peer-reviewed and unpublished studies (e.g. doctoral theses scrutinised at Viva) or grey literature (research published by charities) in the SLR to reduce publication bias inherent to reviews only assessing peer-reviewed journals (Adams et al., 2016) and provide a more balanced view of the evidence (Paez, 2017). However, to uphold scientific rigour, all data was held to the same quality appraisal. I have summarised these below In Table 3.

Table 3: Inclusion and exclusion criteria for the SLR

Inclusion	Exclusion
Written in English or available in English translation but based within the UK.	Not available in English or conducted outside of the UK.
Published in, or after the year 2000.	Published before the year 2000
Peer reviewed journals or grey literature of a good scientific standard	Literature which did not meet at least seven of the nine criteria on the Critical Appraisal Skills Programme (CASP) quality appraisal tool (CASP, 2018) and whose contribution to the literature is not deemed to be high
Deep-dive focus on attitudes or narratives	Focus was too superficial or purely explored what might be considered factual knowledge.
Focus was on HPV as a virus, a diagnosis or receiving a positive result, or speaking to the nature of HPV which makes it different to other cancer causes or vaccinatable infections.	Highly focussed on vaccination more generally or the experience of cervical screening, rather than broader attitudes towards the diagnosis
Research conducted on a general population sample (this included women who may have attended cervical screening previously, or have been invited but not attended screening, but did not include women who have previously tested positive or received an abnormal screening result).	Research conducted on healthcare professionals (e.g. Junior Doctors or Nurses whose role includes supporting patients with HPV) or a clinical sample (e.g. women who have tested positive or received an abnormal result).

Screening Procedure. The literature search was carried out by the lead researcher between February and May 2024 with the final search taking place on the 28th May 2024. Each term was searched independently and then combined using Boolean operators AND and OR. The following databases were searched: Scopus, CINAHL, Medline, Pubmed and PsychArticles. These databases were selected in line with recommendations from the University Librarian. The following third sector organisation websites were also manually searched for any unique research meeting the above criteria: Cancer Research UK, The Eve Appeal, Cochrane, Jo's Cervical Cancer Trust, Ovacome, Ovarian Cancer Action, Macmillan Cancer support, Go Girls, Target Ovarian Cancer, UK Cervical Cancer, The HPV and Anal Cancer Foundation, Throat Cancer Foundation, Oral Health Foundation, Terence Higgins Trust, Jabs for the Boys, GRACE Charity, Oracle Cancer Trust and Mouth Cancer

Foundation. Backwards and Forwards citation searching was then completed for all included papers.

All titles and abstracts were exported from databases and imported into Covidence, an online software to manage the process of SLRs. Papers found via charity websites were downloaded and imported. The first stage of screening was title and abstract screening, followed by full-text review at the second stage of screening. All titles and abstract were initially screened by the lead researcher, followed by another trainee clinical psychologist. All full-text reviews were completed by the lead researcher and another trainee clinical psychologist. Any conflicts were discussed and resolved at both stages. Where a decision could not be reached, these were reviewed and resolved between the main researcher and primary supervisor at both stages.

Quality Assessment. The quality of the studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (CASP, 2018). This checklist was chosen due to its endorsements by Cochrane (Cargo et al., 2018) and the World Health Organisation for use in the synthesis of qualitative research. In addition, the CASP tool was designed for use within health-related research areas (Long et al., 2020) which therefore made this tool appropriate to appraise the current topic of research.

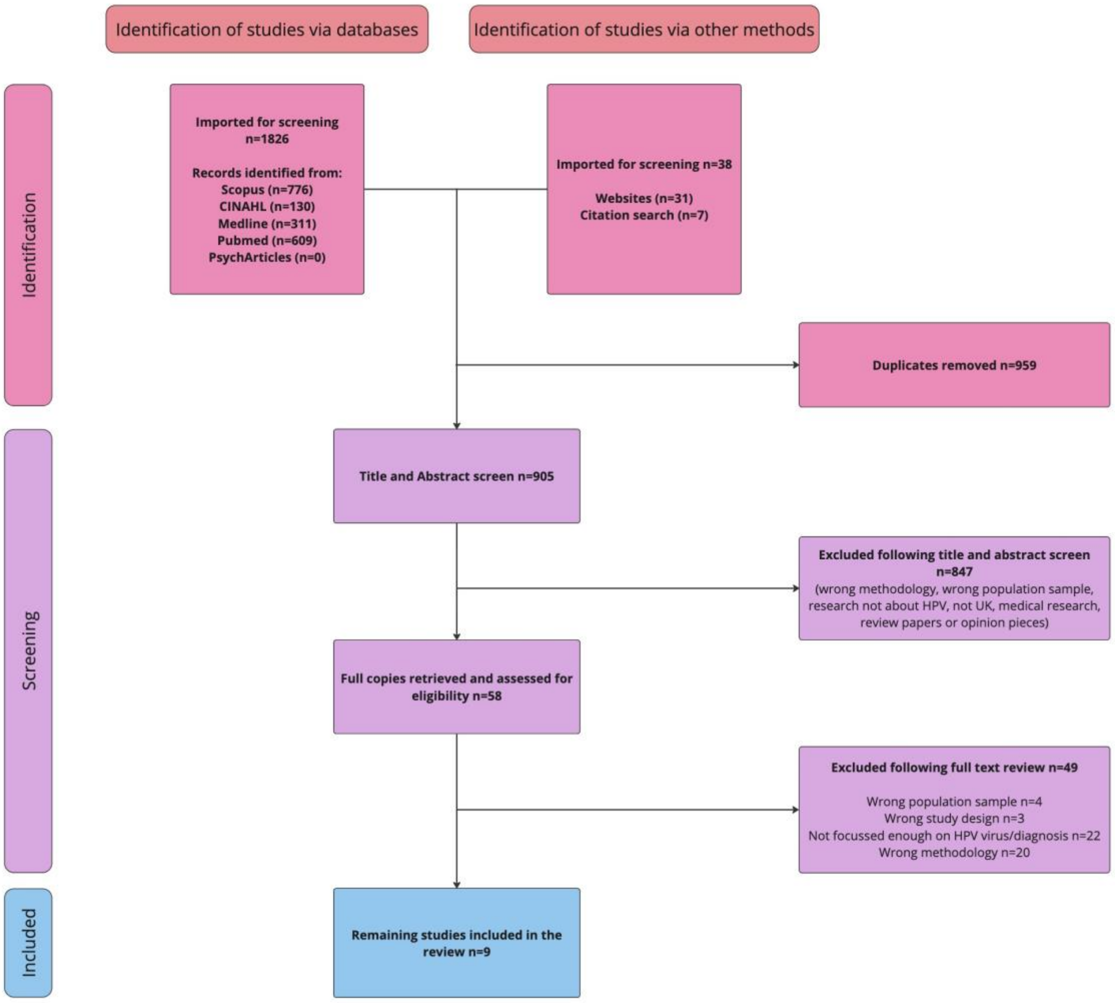
Synthesis Method. Thematic synthesis was deemed appropriate as it was initially developed for use in health promotion and public health (Thomas & Harden, 2008). To do this, the following steps outlined by Thomas and Harden (2008) were followed: (1) coding text, (2) developing descriptive themes and, (3) generating analytical themes. The selected papers were imported into Nvivo, and both first and second order data was included for analysis. Nvivo 14.24.0 was used to code the data and identify descriptive and analytic themes.

Results

Study Selection. A total of 1826 articles were identified and imported into Covidence for screening. An additional 38 papers from Charity websites and through citation searching were identified and imported into Covidence. 959 duplicates were removed, and title and abstract screening was completed on 905 articles. 847 articles were excluded, and 58 full-texts were imported into Covidence for review. Of these 58, nine unique studies were included in the current review. An outline of this can be seen in Figure 1. At title and abstract screening stage there were 35 conflicts and 870 agreements between reviewers, which were resolved via discussion between the main researcher and the first additional reviewer. At full text review stage, there were seven conflicts and 51 agreements. All seven conflicts were resolved through discussions with a third reviewer.

Quality Appraisal. The results from the CASP checklist can be seen in Table 4. It was difficult to make definitive yes or no decisions when the authors had only described some aspects of the CASP item well (e.g. the recruitment and consent process, but less attention was paid to ethical issues) and so I adopted an additional response of "partially met" previously used by Long et al (2020), to attend to nuance. The data appearing to be of slightly lower quality was not considered to be any less rich in terms of its contribution to the understanding of attitudes and beliefs regarding HPV (Carroll et al, 2012), and this method has shown little difference in agreement when compared to more structured quality appraisal methods (Dixon-Woods et al, 2007). Therefore, I chose not to exclude any studies as they all met most of the criteria. Instead, a review of the themes was completed to assess the impact of removing lower quality studies from the analysis. When reviewing the themes, none of the primary themes rely solely on data extracted from the three studies (Cadman et al., 2015; Hilton & Smith, 2011; McCaffery et al., 2003) which could potentially be argued are of lower quality (Carroll et al., 2012). Finally, when considering the research from a decolonising perspective, two of the three studies contained a substantial number of participants from under-researched groups, such as those

Figure 1: PRISMA flowchart of study selection procedure



from minoritised backgrounds and religions. As research suggested that often these groups may be under-researched due to decisions made by investigators (Bibbins-Domingo & Helman, 2022), I included these studies to counteract potential biases and based on the belief that they contributed significant understanding.

Study characteristics. I only analysed the qualitative data from the studies, therefore the characteristics reported below only relate to the qualitative arm of the papers. Table 5 provides an overview of each study in terms of aims, design, sample size, participant characteristics, any inclusion or exclusion criteria, whether information was given about HPV as part of the design, the data collection, data analysis, summary of findings, and strengths and limitations.

Most studies were qualitative (n=7) and the remainder (n=2) were mixed-methods. The studies varied in terms of location, with most in England (n=8) and one (n=1) across both Scotland and England. The sample sizes varied from 10 to 87. Overall, more women (n=251) than men (n=57) were recruited, with a small number of transgender participants (n=3). The ages of participants ranged from 12 to 63, with two studies not reporting age. For studies that did report ethnicity (n=7), 71 participants identified as White, 47 participants identified as Black British, Black American, or African, or Caribbean, 68 participants identified as British Asian or British South Asian, South Asian, Chinese or Asian, two participants identified as mixed-race and two were not reported. Most data were collected via focus groups (n=4), others used semi-structured interviews (n=3) and the remainder was a mix (n=2). Five studies used framework analysis and the other four, thematic analysis

Table 4: Quality appraisal of included studies (CASP, 2018)

Author, year	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Cadman et al., 2015	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Partially met	The first study to explore attitudes in Hindu women, highlighting cultural understandings of HPV and generational differences
Fisher et al., 2024	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Highlighted gaps in beliefs that might be specific to certain sub populations of the UK

Author, year	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Hilton & Smith, 2011	Yes	Yes	Yes	Yes	Yes	Cannot tell	Partially met	Yes	Yes	Highlighted confusion and societal beliefs in perceived risk of HPV in the context of vaccine acceptance
Martin et al., 2011	Yes	Yes	Yes	Yes	Yes	Partially met	Yes	Yes	Yes	Emphasised implications for female only vaccination and testing in feminisation of HPV
McCaffery et al., 2003	Yes	Yes	Yes	Yes	Yes	Partially met	Partially met	Yes	Yes	Findings emphasised distress associated with the introduction of HPV testing across cultures within the UK

Author, year	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Mupandawana & Cross, 2016	Yes	Yes	Yes	Yes	Yes	Partially met	Yes	Yes	Yes	Highlighted beliefs of promiscuity associated with HPV within African parents and the role of culture and religion as perceived protective factors
Nadarzynski et al., 2017	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Emphasised the association of HPV as a women's health issue and explored the impact of stigma for MSM.

Author, year	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Taylor et al., 2024	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Findings highlighted uncertainty about HPV, a high sense of trust in health care systems and difficulties talking about sex and HPV
Williams et al., 2011	Yes	Yes	Yes	Yes	Yes	Cannot tell	Partially met	Yes	Yes	Highlighted the importance of informed choice in healthcare procedures in relation to HPV, and the role of beliefs about sexual behaviour and HPV

Table 5: A summary of the studies included in the SLR

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
1	Martin et al. (2011)	To explore the views of UK university students on the HPV vaccine, cervical cancer and genital warts	Sample size: N=34 Males: N=17 Females: N=17 Age range: 19-24 Ethnicity: Not reported Location: England Setting: Leeds University students	Study design: Qualitative Data collection: 2 male focus groups, 2 female focus groups Data analysis: Thematic analysis	No	○ Knowledge and understanding of HPV, impacts on health, and development of cervical cancer was low. ○ Associations with Genital Warts prompted links to promiscuity and unprotected sex, with warts being seen negatively due to their visibility. ○ Lack of awareness that HPV can impact men's health. ○ HPV is seen as a women's health issue. ○ Concerns the HPV vaccine will increase sexual complacency and unsafe sex and promote sexual health as solely women's responsibility.	– Methodology captured dominant discourses and mimics the way in which sexuality is shaped relationally. – This research included under researched voices – A question guide was developed and piloted and facilitators were trained. – The research used peer facilitators to encourage openness. – Analysis was done by 3 researchers – Cannot be generalised due to limited sample size – Saturation of topics within the groups was not achieved. – Participants were self-selecting. – Participants were not compensated for their time

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
2	Williams et al. (2011)	To examine knowledge about HPV and attitudes towards HPV vaccination among girls in the 'catch-up' age range using qualitative methods.	Sample size: N=10 Females: N=10 Age range: 17-18 White British: N=8 British Asian: N=2 Location: England Setting: A secondary school and college in Kent and Somerset	Study design: Qualitative Data Collection: Semi-structured interviews Data analysis: Framework analysis	No	o Knowledge of HPV and cervical cancer was low, including how to protect against HPV. HPV was associated with higher numbers of sexual partners or promiscuity and therefore often viewed as low risk for most. o There was a desire for more information about HPV, the vaccine and link to cervical cancer o Sexual transmission of HPV may impact decision making for the vaccine in some girls. o The HPV vaccine was not seen as encouraging sexual complacency	+ A balanced sample of vaccinated/unvaccinated participants. + A topic guide was developed with justification + All authors were involved in development of themes + Clinical implications for the findings are suggested. – Interviews may be too short to explore in-depth – Majority of the sample were White British. – No specific further areas of research are suggested. – Verbatim quotes are not provided for every sub-theme. – There were difficulties recruiting unvaccinated girls which may suggest the sample is not representative.
3	Taylor et al. (2024)	To find out what mothers of girls age 11–18 know and think about HPV and HPV vaccination, cervical cancer and cervical screening and to	Total sample size: N=138 Focus groups or interview sample size: N=15 Female: N=15 Age range: 35-51	Study design: Mixed methods Data collection: Survey, Focus groups and semi-structured interviews Data analysis:	Yes	The survey results suggest o Most participants attended screening and understood its purpose. o Most participants had a vaccinated daughter	+ An interview schedule was provided for transparency + Multiple authors were involved in naming themes and selecting quotes + Future research was suggested + Clinical implications were discussed

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
		explore whether the vaccination invitation is a good opportunity to nudge mothers to attend cervical screening	White British: N=15 Location: England Setting: Mothers who's daughters are attending school in Staffordshire	Descriptive statistics and Thematic analysis		and knew they still needed to attend cervical screening ○ Some participants were able to identify causes for cervical cancer, with most having heard of HPV. The qualitative results suggest: ○ Mothers had limited knowledge about HPV and cervical cancer, but better knowledge of Cervical screening ○ All mothers expressed a desire for more information ○ Many did not discuss the vaccine with their daughters, and some felt they were too young. Mothers thought this education should come from school Some mothers felt embarrassed to try and discuss HPV with their daughters.	– Only one author completed the coding phase of analysis – A majority of the focus group sample were White British, well educated, employed, with high household income. – The sample size was small – Methodology changes due to no-show of other focus group participants.

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
4	McCaffery et al. (2003)	To examine attitudes to HPV testing within primary cervical screening among a sample of women purposively selected to provide contrasting religious and cultural beliefs and practices, which could influence attitudes and experiences related to HPV testing.	Sample size: N=71 Females: N=71 Age range: 20-59 African-Caribbean: N=16 Indian: N=19 Pakistani: N=20 White British: N= 16 Location: England Setting: Women eligible for cervical screening with the Greater Manchester service	Study design: Qualitative Data collection: Focus groups Data analysis: Framework analysis	Yes	○ The link between HPV and cervical cancer via sexual transmission provoked a range of emotional responses. ○ There was confusion between high-risk and low-risk HPV. HPV was thought of as stigmatised due to its link to Genital Warts ○ Participants had a range of negative and more positive responses to the idea of testing positive for HPV. ○ Concerns about the impact on the trust in their relationships were highlighted ○ Concerns of HPVs association to promiscuity or sex outside of a marital relationship.	+ A large sample was recruited + The study used purposive sampling to recruit a diverse set of women + The study included participants of less researched participants + Analysis was completed by two authors + Clinical implications and future research suggestions are made – Recruitment and consent details are limited. – The topic guide shows limited information. – The results section could be clearer when reporting participant quotes.

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
5	Hilton & Smith (2011)	To explore adolescent girls' understandings of HPV and its link with cervical cancer, and experiences of vaccination following introduction of the vaccination. The study also aimed to identify gaps in knowledge	Sample size: N= 87 Females: N=87 Age range: 12-18 Ethnicity: not reported Location: England and Scotland Setting: Girls who have been offered the vaccine living in parts of England and Scotland	Study design: Qualitative Data collection: Focus groups Data analysis: Framework analysis	No	o HPV related knowledge was limited. o Those who understood the transmission of HPV believed their risk to be low, due to associations with promiscuity. o Girls were uncertain about how HPV is detected There was some awareness of the link to cancer and the vaccine, but this varied. o Most girls were aware of Cervical screening	– Topic guide provided, and its development and testing described. – The researchers highlighted attention to deviance within the data – A large sample size was recruited across the UK. – The researchers acknowledged that it was not always possible to identify which participants were speaking – Only a minority of the sample were unvaccinated. – Girls self-selected to volunteer for the study, which might have impacted the opinions and beliefs captured.
6	Cadman et al. (2015)	To explore the attitudes and understanding of Hindu women towards cervical screening, HPV testing and self-collected HPV samples and to ascertain their views on two different self-collection devices: the Dacron swab	Total sample size: N=134 Focus groups sample size: N=23 Female: N=23 Age range: 23-63 Indian: N=18 Asian Other: N=2 White Other: N=1 Unreported ethnicity: N=2 Location: England	Study design: Mixed methods Data collection: Survey and Focus groups Data analysis: Chi-square test, logistic regression and Framework analysis.	Yes	They survey results suggest o The cervical screening rates of the sample were below UK average. o Women who were single were less likely to attend. o Women who were born outside the UK or India, or had children were more likely to attend.	+ Interview guide given for transparency. + Participants were compensated for their time and travel costs. + The research was supported by community members + The impact of using a translator women's ability to talk freely was considered. + Multiple researchers completed analysis – Reporting of demographic information is unclear.

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
		and the Evalyn brush.	Setting: Women attending BAPS Shri Swaminarayan Mandir.			○ Barriers to attending were listed as: fear of pain or cancer and, embarrassment. The qualitative results suggest: ○ Women had good knowledge of Cervical screening ○ Some awareness of link to sexual activity, but link between HPV and cervical cancer was unclear ○ Women perceived a HPV+ result would impact relationships with partners, family and communities. ○ There was expected to be generational differences in how a positive result was received.	– Women were recruited at a health event and perhaps already more interested in HPV and women's health. – Sample cannot be generalised as this group of women is described as less diverse than the Hindu UK population.
7	Nadarzynski et al. (2017)	To explore the perceptions of HPV, and attitudes towards HPV vaccination to inform the development of future interventions on HPV vaccination	Sample size: N=32 Male: N=29 Transgender: N=3 Age range: 18-40 White: N=27 Asian: N=2 Mixed-race: N=2 Chinese: N=1 Location: England	Study design: Qualitative Data collection: Focus groups and semi-structured interviews	Yes	○ Awareness of HPV was limited and perceived to be a women's health issue. ○ Men had limited knowledge of Anal or Penile cancer and increased risk for MSM.	+ Focus groups and individual interviews for range and depth of views + Interview schedule and development was described. + Interviewers were trained. + Participants were paid. + Multiple researchers completed analysis

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
		for Men who have sex with Men (MSM) in the United Kingdom.	Setting: Men and Transgender folk living in or visiting Brighton and Hove	Data analysis: Framework analysis		○ Beliefs that HPV risk was low, with some believing it to be rare, and others believing it to be common. ○ Some believed it was linked to promiscuity. ○ Men were not certain on preventative methods ○ Confusion between high-risk and low-risk HPV and concerns of stigma linked to Genital Warts Concerns of marginalisation with parallels drawn to Gay men and HIV.	+ The participants included diverse sexuality and genders. – Most of the sample were White British – The social and cultural norms in Brighton might be different to other areas in the UK due to its high LGBTQ+ population. – Participants were given relative risk figures for HPV related cancer, which has been shown to alter perceived vulnerability.
8	Mupandawana & Cross (2016)	To explore attitudes towards HPV vaccination among UK based African parents of daughters aged between 8 years and 14 years.	Sample size: N=10 Male: N=5 Female: N=5 Age range: Not reported African: N=10 Location: England Setting: African parents living in a city in the North of England who have at least one daughter aged 8-14	Study design: Qualitative Data collection: semi-structured interviews Data analysis: Thematic analysis	No	○ Low awareness of HPV and cervical cancer and found the vaccine to be unacceptable. ○ False beliefs were held despite information given by school ○ Discomfort discussing the vaccine with children due to links to sex. ○ Beliefs that the vaccine was only for	+ Participants recruited via gatekeepers from a community group. + Interviews with Fathers as well as Mothers, separately to gain unbiased data. + Ethics explained in detail. + Member checking with participants + Researchers reflected on positioning of a black woman interviewing black men and the impact this may have due to cultural considerations.

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
						promiscuous girls, or that the vaccine would encourage sexual activity. ○ Beliefs that culture and religion would act as protective factors against HPV. ○ Beliefs that cervical cancer in African women is linked to traditional medicines rather than HPV.	– Participants were not paid for their contributions – The sample size was small. – No demographic information was collected
9	Fisher et al. (2024)	To explore the Information needs of vaccine-hesitant, ethnically diverse parents for decision-making about the HPV vaccine for their adolescent child.	Sample size: N=29 Male: N=6 Female: N=23 Age range: Not reported Somali N=10 White British N=4 British African N=3 Bengali: N=2 Black British: N=2 African: N=1 Black: N=1 Black African: N=1 Black American: N=1 Black Caribbean: N=1 British Asian: N=1 British South Asian: N=1 Sudanese: N=1	Study design: Qualitative Data collection: Semi-structured interviews Data analysis: Thematic analysis	No	○ Limited knowledge about HPV and the vaccine. ○ Belief that adolescents are healthy and do not need health interventions ○ Desire for more knowledge ○ Difficulties acknowledging link between HPV and sex, linked to cultural and religious expectations, and the maturity of their children. ○ Generational differences in beliefs noted.	+ Detailed interview guide provided for transparency + Interviews completed in participants preferred language + Coding was checked with a second analyst. + Large sample size + Diverse participants recruited from mixed culture and backgrounds with mix of first-languages – Majority of the sample were female – The findings are not representative of all ethnicities with low vaccine uptake. – Participants were not compensated for their time. – There is no discussion of reflexivity.

Paper number	Author (year)	Study Aim(s)	Sample Characteristics	Methodology	Information about HPV given as part of the design?	Summary of Findings	Strengths and Limitations
			Location: England Setting: Parents in London or the Southwest of England who had been invited to vaccine their adolescent child against HPV.			○ Desire for sexual education over the vaccine. ○ The stigmatisation of the HPV vaccine due to its link to sexual activity. ○ Concerns that vaccination would encourage sexual activity in children and adolescents.	

Synthesis of findings. Six main themes and fourteen sub-themes were developed. The main themes were: (1) Sense of uncertainty, (2) myths and misconceptions, (3) differences in beliefs, (4) The impact of gender and sexuality, (5) The anticipated impact of testing positive for HPV, and (6) the perception of risk. These themes are discussed below[4]. Additional quotes can be seen in Table 6.

Theme 1: Sense of uncertainty.

Sub-theme 1: The use of uncertain language. Detailed knowledge of HPV and it's role in development of cancer was limited across groups[1][3][5][6][7][8][9], with many expressing confusion through the use of uncertain language, for example "For me, I've not heard…I've not heard a clear message on the news or in the newspapers" (Taylor et al., 2024). Many participants were also unclear on the impact of HPV for boys and men, associating HPV with women's health following implementation of the HPV vaccine, as demonstrated by one participant stating "I didn't know the boys could have it, how long has this been around for? Is it proven benefits?" (Fisher et al., 2024). Whilst some female participants seemed to be aware of the impact for men, many male participants were unaware[1][7]. There was also a lack of clarity around how HPV is tested for with several indicating routine STI testing, "Lorne: But you won't find HPV in an STI screening. Sally: What do you mean? Lorne: They won't be looking for it" (Hilton & Smith, 2011) Often, hrHPV was confused with lrHPV with one participant saying "the word cancer is scary enough and now this new wart virus will cause many of us to be wary" (McCaffery et al., 2003)[1][3][7].

Sub-theme (2) Desire for more information. Across several studies there was a desire for more information[3][4][7][9], reflected in either direct questions asked to the interviewer, for example "What is the difference? I don't understand," (fisher et al., 2024)[3][7], or was stated explicitly "I wanted, like, a proper booklet that I could

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[4] The papers have been numbered from one to nine. When discussing a finding from the synthesis the numbers denoted in brackets represent the papers from which the findings are represented. These numbers can be seen in Table 5.

read through," (Williams et al., 2011)[2][4][7][9]. This was true even for girls[2] or parents of vaccinated children[3][9]. Generally, participants wanted to know more about HPV[4][7], transmission[4] and how it causes cancer[3]. Some also referred to the importance of available information for the whole "community" (McCaffery et al., 2003).

Theme 2: Myths and misconceptions.

Sub-theme 1: How to prevent HPV? Across groups there were different beliefs held about protecting against contracting HPV, with many people believing usual methods of contraception to be effective such as: hormonal birth control[5], condoms[1][2][5][7], and abstinence, with one participant suggesting "let's ignore it we are not having sex," (Cadman et al., 2015)[4][6][5]. Parents held the belief that providing good sex education and encouraging monogamous relationships would lower risk[8][9] because this would "prevent them from engaging in 'risky' behaviour" (Fisher et al., 2024).

Sub-theme 2: Sexual behaviour and complacency. HPV was often associated with promiscuity[1][4][5][6][8] [9], with one participant associating it with girls who "sleep around" (Hilton & Smith, 2011). This then sometimes informed vaccine decision-making, with one parent describing the HPV vaccination as "a vaccine for prostitution" (Mupandawana & Cross, 2016). Some parents were concerned that vaccination would be seen as encouraging sexual activity too young[2][8][9]. This belief was sometimes echoed by young people who worried that accepting the vaccine would lead to complacency or sexual risk-taking[2][5]. Not everyone linked HPV to promiscuity[1][2][7][8][9], with some holding more pragmatic beliefs, for example one parent stated "she can be infected by the one boy she sleeps with, or the man she marry" and another sharing "I'm aware of what's out there and how easy it is to pick up something," (Mupanadawana & Cross, 2016), suggesting these individuals were aware of how common HPV is.

Theme 3: Differences in beliefs.

Sub-theme 1: Cultural or Religious differences. Narratives and attitudes held about HPV were also linked to culture, with people from African, Pakistani and Indian backgrounds believed to be at lower risk for HPV because of a “good upbringing” (Mupanadawana & Cross, 2016) and the expectation that individuals will not engage in sexual activity until they are older[4][8]. Therefore, multiple sexual partners was not seen as a relevant risk factor[4][8]. Some parents also assumed that girls from white backgrounds were more likely to engage in sexual activity at a younger age, emphasising ideas of HPV as a “white people’s disease” (Mupanadawana & Cross, 2016). This difference was perhaps due to most media coverage being linked to Jade Goody. Some also attributed development of cervical cancer within African women to the prolonged use of traditional medicines, and therefore associated the diagnosis with older women[8]. Religion was also cited as a protective factor by parents whose children were “not supposed to have a sexual intercourse without getting married” (Fisher et al., 2024)[1][8]. Some were also concerned that by attending HPV testing this could cause community members to suspect that someone is living outside of the religious and cultural expectations held by members of Catholic or Islamic communities with one woman stating “being single, my family will be suspicious of me [if I go for HPV testing],” (McCaffery et al., 2003). However, some women also highlighted that attending cervical screening is looking after your health and therefore that of your family which would be supported by Islamic beliefs[4].

Sub-theme 2: Talking about sex and HPV. Difficulties discussing HPV and sex in general were highlighted by several studies[1][2][3][6][8][9], with some links to cultural differences in these conversations[8][9]. For example, in some African cultures it is customary for the Auntie to hold this role, and the research highlighted these lost connections due to immigration[8]. However, many parents described trying to hold these conversations[3][9], despite difficulty as one participant said “I like to be honest with my kids and discuss anything even though it’s difficult especially within my culture" (Fisher et al., 2024). Overall, many people described these conversations to be associated with "perceived embarrassment," (Taylor et al., 2024) or shame[1][2] [3][8][9]. When considering disclosure, those from older generations felt that it would be more difficult for a person from an older generation to disclose HPV compared to those from younger generations[6].

Theme 4: The impact of gender and sexuality.

Sub-theme 1: Sexual health is women's responsibility. Concerns were highlighted by some of the societal association between HPV and cervical cancer[1][7], and the general lack of awareness of the impact for the health of boys and men[5][7]. Many participants suggested that this encourages more complacency from heterosexual men, as it perpetuates ideas that sexual and reproductive health are women's responsibilities, as one woman stated "this may be a bit of a feminists view, but doing it like this is going to send out the message that sexual health is a woman's responsibility" (Martin et al., 2011)[5]. There were parallels drawn to narratives around other STIs such as chlamydia, whereby boys or men perhaps considered this to be less of a priority as it has a greater impact for women, and to contraception and how girls are often expected to be using some form of birth control by male partners[1].

Sub-theme 2: Should boys be protected too? There was a sense of injustice for men who had not been given the information or the option to protect themselves from the potential impact of HPV[1][7], as one man shared the following frustrations "what are they gonna do? Cos it seems to me like it's all men, not just gay and bi men." (Nadarzynski et al., 2017). However, some men highlighted concerns that links between HPV and feminine issues could impact how seriously men and boys consider future health interventions for HPV[7]. Furthermore, whilst men who have sex with men (MSM) felt it was important to be aware of their heightened risk from HPV, there were also concerns that these narratives could become marginalising, and parallels were drawn to those associated with HIV for MSM[7].

Theme 5: The anticipated impact of testing positive for HPV.

Sub-theme 1: HPV Stigma. The topic of stigma arose in the context of association with other STIs[4][7], sex[9], or multiple sexual partners[7][8]. Interestingly, the link to genital warts was also discussed, with many believing this could add to the stigma of HPV[1][4][7]. It was suggested that this was linked to the visibility of genital warts and being unable to hide the infection[1][4][7], as one participant described "if I was going to be sleeping with a man that had one, I'd be a little bit turned off," (Nadarzynski et al., 2017). Some referred to genital warts as "one of the worst things you can get," (Martin et al., 2011) and in some cases the emotional response seemed intense[1][7] despite no links to long-term health concerns.

Sub-theme 2: Blame. Across the studies, many alluded to a sense of blame[1][4][5][8]. It was suggested that they would consider their sexual history and "if I tested positive I would worry who I had slept with" (McCaffery et al., 2003). Others were concerned their partners might blame them[4]. Finally, there was also a sense that blame for HPV belonged to the infected individual with one participant saying "if people want to be promiscuous, let them pay for their sins" (Mupandawana & Cross, 2016), and some others fearing this response from others, should they test positive[1].

Sub-theme 3: Trust in relationships. Many were concerned about the impact on trust in their relationships with their partners[4][6], children[6], and the wider community[4][6]. Some believed their partner would lose trust in them[4], and others believed they would think that their partner had been unfaithful with one woman stating "I will mistrust my husband," (McCaffery et al., 2003). Some even believed that a HPV test could accurately test your partner's fidelity[4]. Finally, some individuals also suggested that a positive test result would impact how they are viewed by family and their communities[4][6].

Sub-theme 4: The emotional impact. A strong emotional response to testing positive was expressed, with many suggesting fear [4][6][7] or worry for their health, especially cancer[4][7], and in knowing that they had contracted an STI[4][7]. Some expressed the importance of this being discussed properly with a medical professional with one woman saying "they shouldn't…come out with a letter to say you've got this virus. They can say go to your GP," (Cadman et al., 2015). However, for some individuals, the response was less distressing, with some alluding to cancer being just another part of life[7], and others suggesting reassurance in knowing that they can catch something early, with one woman stating "it would reassure me I suppose, if I hadn't had it done, I wouldn't know if I'd got it…" (McCaffery et al., 2003).

Theme 6: The perception of risk.

Sub-theme 1: Differences between generations. There was a difference in perceived risk of HPV across the lifespan with many believing that adolescents are too young and "strong" (Fisher et al., 2024) to be impacted and therefore do not need vaccinating[8][9]. Furthermore, there was a belief that cervical cancer is a bigger issue for older women[8][9], perhaps due to narratives around when an individual is likely to engage in a sexual relationship. However, some parents were concerned that the age of sexual activity is getting younger as one parent says "I hear girls as young as 11 are having sex with their boyfriends" (Mupandawana & Cross, 2016), and this was highlighted as a reason for accepting the vaccine[9]. Some participants also acknowledged how attitudes towards this may have changed, with older generations feeling the vaccine to be less necessary[6][9].

Sub-theme 2: Risk associated with HPV. Many perceived risk of HPV to be low[1][2][7][8][9]. Some parents believed their child was not at risk because they were not engaging in behaviours they associated with hr HPV such as "partying" or "getting drunk" (Fisher et al., 2024). The lack of visible symptoms associated with HPV was cited as a reason to believe that the risk was low[7], alongside concerns for other STIs which were considered to be riskier, such as HIV[7]. One girl also perceived low risk because “I don’t have as many sexual partners or anything like that. I use protection,” (Williams et al., 2011). Furthermore, some felt uncertain about risk due to the lack of personal connection or experience of HPV related cancer[7].

Table 6: A summary of themes, sub-themes and corresponding quotes

Themes	Sub-themes	Quotes
Sense of uncertainty	The use of uncertain language	"Is it a contributory factor or does it cause it? For me, I've not heard… I've not heard a clear message on the news or in the newspapers" (Taylor et al, 2024) "Well isn't it true that 50 per cent or something of the sexually active people would test for HPV anyway?" (Martin et al, 2011) "I didn't realise this was an issue for men. I've heard of HPV because when I was at school all the girls had to have vaccinations" (Nadarzynski et al, 2017) "And you're more likely to get it if you've had genital warts and stuff aren't you, from what I believe" (Taylor et al, 2024)
	Desire for more information	"we need to educate the community" (McCaffery et al, 2003) "there was no number or email address. I wanted to get information on it but I wanted, like, a proper booklet that I could read through" (Williams et al, 2011)
Myths and misconceptions	How to prevent HPV	"I'm not in a rush to get it [the HPV vaccine] because I don't have as many sexual partners or anything like that. I use protection" (Williams et al, 2011) "Some parents emphasised a preference to provide education to their adolescent child to prevent them engaging in 'risky' sexual behaviours" (Fisher et al, 2024)

	Sexual behaviour and complacency	“It was common for the girls who did know that HPV was sexually transmitted to believe that their own risk of contracting it was low because they associated HPV infection with girls who ‘sleep around’” (Hilton & Smith, 2011)
		“‘I feel like children are encouraged to be sexual and 12 years old is basically too young to deal with those stuff.” (Fisher et al, 2024)
		“…she can be infected by the one boy she sleeps with or the man she marry.” (Mupandawana & Cross, 2016)
Differences in beliefs	Cultural or Religious differences	“A good upbringing was perceived as protection by both mothers and fathers, with HPV infection perceived as an infection for children who come from uncultured, non-African backgrounds” (Mupandawana & Cross, 2016)
		“Its [cervical cancer] caused by the medicines women wear [insert in their vaginas]” (Mupandawana & Cross, 2016)
		“Being single, my family will be suspicious of me [if I go for HPV testing]” (McCaffery et al, 2003)
		“Others felt that Islamic beliefs would support HPV screening as good for women’s health, and hence family health.” (McCaffery et al, 2003)

	Talking about Sex and HPV	“A barrier to communicating between mothers and their daughters was the mothers’ perceived embarrassment of talking about these topics” (Taylor et al, 2024)
		“‘I like to be honest with my kids and discuss anything even though it’s difficult especially within my culture, it’s not something that we discuss.” (Fisher et al, 2024)
		“HPV disclosure would not be such a problem for the younger generation: ‘they are broad minded, they are not like us … if someone knows or not they don’t worry’” (Cadman et al, 2015)
The impact of gender and sexuality	Sexual health is a woman’s responsibility	“It sends a message that it’s a girl’s responsibility. It’s a girl’s responsibility to be on the pill and its just perpetuating that” (Martin et al, 2011)
		“Even in the male groups, there was a consensus that men don’t really think about chlamydia as “it isn’t that big an issue ‘cos it only affects women”” (Martin et al, 2011)
	Should boys be protected too?	“What are they gonna do? Cos it seems to me like it’s all men, not just gay and bisexual men. So they should just offer it with the girls at school.” (Nadarzynski et al, 2017)
		“My first thought would have been [boys are vaccinated] to protect females…” (Fisher et al, 2024)
		“Services that are exclusively given to women I suppose seem feminine. I can imagine that there are some people who would resist against something if they thought it had feminine associations to it” (Nadarzynski et al, 2017)

		"I don't think people will like it. Since they just got rid of HIV labels and they don't want another stigma again" (Nadarzynski et al, 2017)
The impact of testing positive for HPV	HPV Stigma	"It's one of the worst things you can get because you can see it and it's a sign that you've been promiscuous and that you're having unprotected sex." (Martin et al, 2011)
		"The appearance of genital warts was reported to be disturbing and distressing, being described as 'disgusting', 'awful', 'scary', or 'atrocious'." (Nadarzynski et al, 2017)
		"If you had warts then the stigma is definitely worse 'cos they're so obvious if you have them and they're like right there in front of you. If I went and told someone I had HPV, its just a virus then I'm sure most people will be like, "hmm oh right, well I hope you get better", without even a second thought and they won't associate it with you being promiscuous or anything at all 'cos they don't know about it" (Martin et al, 2011)
	Blame	"If I tested positive, I would worry who I had slept with" (McCaffery et al, 2003)
		"My husband will deny giving it to me and will accuse me of sleeping with someone else" (McCaffery et al, 2003)
		"She [Jade Goody] could've stopped that a lot sooner. (Hilton & Smith, 2011)
		"If people want to be promiscuous, let them pay for their sins" (Mupandawana & Cross, 2016)

	Trust	"If you know you are positive then it disturbs your relationship with your partner" (Cadman et al, 2015) "We will know if our husbands are being faithful or not" (McCaffery et al, 2003) "testing positive for HPV was also suggested as implying promiscuity and sexual activity to others such as family (particularly parents) and friends" (McCaffery et al, 2003)
	The emotional impact	"I will be heartbroken and worried for my health and for my family" (McCaffery et al, 2003) "Women commented that they would find a positive result "frightening" and that "they shouldn't … come out with a letter to say you've got this virus. They can say go to your GP" (Cadman et al, 2014) "I suppose we also sort of live in the world where everything can cause cancer apparently. You have to kind of level itself out I suppose" (Nadarzynski et al, 2017) "It would reassure me I suppose, if I hadn't had it done, I wouldn't know if I'd got it" (McCaffery et al, 2003)
The perception of risk	Differences between generations	"They're teenagers, they're strong, and so what are they protected against, I don't understand" (Fisher et al, 2024)

		"I think young women getting married are the ones who should be vaccinated" (Mupandawana & Cross, 2016)
		"My mum, she'd go, 'Oh, we won't need that then, no. My child won't need that. It'll be fine.' But no, definitely I'm aware of what's out there and how easy it is to pick up something from someone" (Fisher et al, 2024)
	Low risk associated with HPV	"it wasn't like she was choosing to have a relationship, she wasn't partying, she wasn't getting drunk" (Fisher et al, 2024)
		"It's not something that, you know, being concerned about getting, because HIV they're the ones that are kind of worried about" (Nadarzynski et al, 2017)
		"I think that's serious. Though I still don't know anyone, as I've never had a friend that is a gay man that's had HPV that led to cancer or genital warts" (Nadarzynski et al, 2017)

Implications for Clinical Practice and Research

To my knowledge, this is the first SLR to examine the beliefs, narratives and attitudes held by people in the UK general population. This therefore makes a significant contribution to the evidence base in setting the context for women when they test positive for hrHPV, as it is likely that their experiences are influenced by the views, beliefs and narratives held by wider society.

In terms of strengths, a variety of studies were included ensuring societal narratives from several subgroups of the UK population. For example, participants were recruited from several geographical locations, of a variety of ages, genders, sexualities, ethnicities and cultural backgrounds. A thorough search strategy was implemented with an attempt to include grey literature to reduce bias (Adams et al., 2016). However, it is important to acknowledge that no grey literature was found to meet the inclusion criteria. A final strength of this review was the collaboration between researchers. This allowed for independent screening and review of all identified articles, with the final decision conducted between the researcher and primary supervisor.

In terms of limitations, few studies researched these beliefs and narratives about HPV in isolation, without also considering vaccination or cervical screening. For some, beliefs, attitudes and narratives might have been impacted by an increase in vaccine hesitancy following the COVID-19 pandemic (Leonardelli et al., 2023), alongside other factors also suggested to influence vaccine hesitancy such as race, age, and lower income (Hussain et al., 2022). As many individuals had only heard about HPV due to the vaccine (Cadman et al., 2015; Nadarzynski et al., 2017; Williams et al., 2011), it is possible that this link could have held substantial influence on the beliefs portrayed about the virus. In addition, several studies did not meet all of the desired criteria outlined by CASP (2018), in particular participant and researcher relationship were frequently not discussed, perhaps due to the restrictions on wordcount.

The research reviewed in this chapter, both in the introduction and the SLR contributed to current understanding of how hrHPV is perceived and understood.

The results from the SLR suggested that within the general population there are; myths and misunderstandings about HPV, cultural and religious factors which can impact beliefs, an impact of gender and sexuality, differences in perception of risk to self and, a variety of anticipated emotional responses including fear or stigma, many of which are consistent with research highlighted in the introduction. (McBride, Tatar et al., 2021). For example, several studies in the review discussed the impact of female only testing and targeted vaccination and discussed the implications for this in line with women's level of responsibility and the negative health impacts for boys and men (Allen et al, 2009; Thompson, 2010). However, to my knowledge, no studies thus far have explored the experience of testing positive for hrHPV with a view to consider this layer of context.

Generally, there was uncertainty regarding hrHPV, with many expressing health-related anxiety in anticipation of testing positive and others expressing less concern. People in the UK tended to have unanswered questions, which in turn have been tentatively linked to these higher levels of anxiety or uncertainty (Daley et al., 2010). People in the population have been shown to hold myths and misconceptions, for example that vaccinating adolescents might lead to an increase in sexual activity, a finding also discussed in terms of misleading information published in the media (Forster et al., 2010). Interestingly, many associated HPV with genital warts (lrHPV) and were therefore frightened of the impact of their visibility (Martin et al, 2011; Nadarzynski et al 2017) Finally, the review also highlighted cultural nuances in understanding, for example it suggested that people from some cultures are at less risk from HPV due to a lesser likelihood to engage in risky sexual behaviour. This emphasised the importance of context, and the relevance of individual details in the experience of testing positive for hrHPV not previously explored using idiographic methodologies.

In conclusion, this SLR provided a greater understanding of where emotional responses to hrHPV might originate. For example, if a woman is aware of stigmatising beliefs within society, it is then unsurprising to report that women felt stigmatised. This helped to situate these emotional difficulties within wider systems, rather than as in the individual which has perhaps been the previous framework for considering hrHPV related distress (McBride, Marlow, et al., 2021; McBride, Tatar et al., 2021). Therefore, to explore psychological and emotional distress in response to testing positive for hrHPV in a way in which encapsulates some of this additional contextual nuance, research needs to address this from a position considering someone's unique, individual context.

Research Question

The aim of this study was to explore the emotional experience of women testing positive for hrHPV. Specifically, this study aimed to answer the following question: How do cis-gender women in the UK make sense of the experience of testing positive for hrHPV?

Chapter 2: Method

This chapter overviews the chosen methodology and research design. It also describes the participants, the recruitment strategy, the process of participation, data analysis and quality appraisal.

Design

To explore in-depth, the experiences of cis-women who have tested positive for hrHPV, this required a qualitative approach. Whilst previous research has shown a range of responses to testing positive for hrHPV using quantitative methods (Knight & Roberts, 2021; Sherman & Nailer, 2018; Waller at al., 2003), these studies have rarely been able to understand how or why women had these experiences. In addition, these studies can sometimes show the answer to this question as varied and more complicated than can be understood via quantitative methods alone (Sullivan & Sargeant, 2011). Furthermore, when considering my epistemological stance of critical realism, qualitative methodologies fit better with an approach which considered context and differences between individuals rather than quantitative methodologies underpinned by more positivist approaches (Teherani et al., 2015). Therefore, the design follows that of a qualitative interview study.

Interpretative Phenomenological Analysis (IPA)

As the research question was focussed on exploring experiences in-depth, Interpretative Phenomenological Analysis (IPA) methodology was chosen for analysis (Smith et al., 2022). IPA is a qualitative approach that falls under the category of an experiential qualitative method of data analysis (Smith & Nizza, 2022), meaning that the focus of the analysis is on the content of narratives told by participants about their experiences. The aim of IPA is to reach an understanding of what the experience of study was like for that individual, with researchers attempting to understand this from that specific individual's perspective (Smith & Nizza 2022).

IPA was heavily influenced by three philosophical principles which underpin the creation of this method of study to support analysis of participant experience (Smith & Nizza 2022). The three principles: phenomenology, hermeneutics and idiography are discussed below.

Phenomenology

Phenomenology was originally developed by Edmund Husserl (1859-1938), who argued that the basis for scientific study should begin with the exploration of subjective experience (Smith & Nizza, 2022). The philosophy aimed to understand what aspects of someone's experiences made it unique and different, and to provide a detailed account of ones lived experience and their sense-making (Smith et al., 2022). It was thought that should someone be able to perceive their own experience with enough depth that this would highlight important facets of the experience, which would in turn perhaps shed light on the understanding of this experience in other people (Smith et al., 2022), therefore potentially allowing for comparisons between participants in the later stages of analysis. To do this, it was suggested that previously understood constructs about the world or what we think we know, are put to onside to try to understand the experience from the perception of others (Smith & Nizza, 2022). It was also believed that to get as close as possible to the experience of another, the researcher would need to work reflexively and with the use of bracketing to help set aside these preconceptions (Pietkiewicz & Smith, 2014; Smith & Nizza 2022). Following Husserl, Heidegger (1889-1976) developed phenomenology further, emphasising the importance of how an individual who has had a particular experience is related to the world and society that surrounds them (Eatough & Smith 2017), which would suggest that this individuals experience is only relevant when considered in their particular context. Equally, it emphasises the impact of cultural, societal and other contextual factors on an individuals' experience of a particular phenomenon.

Hermeneutics

Heidegger's development of phenomenology was also influenced by ideas of hermeneutics referring to the interpretation of data, initially in the context of greater understanding of biblical texts (Smith et al., 2022). For IPA, this emphasised how phenomenology needed to be viewed from an interpretative stance (Smith & Nizza, 2022). Heidegger described the process of interpretation to move past the surface level understanding, to uncover a deeper meaning (Smith & Nizza, 2022) based on the premise that meaning could not always be easily understood from observation or initial recollections or accounts of an experience. This is thought to be due to the different levels of meaning making being not only concerned with literal or linguistic analysis of words or text but through to more complex, and interpretative analysis of what someone is actually trying to express when communicating an experience, and more experiential and existential meaning makings concerned with the meaning of major life events, impacts on sense of identity, and meaning of life (Smith, 2019). Therefore, phenomenological study requires attention to detail and ability to identify clues in what is being described through each of these meaning making levels in order to help to support an interpretation of someone's understanding of their experience and its significance.

Heidegger also emphasised the role of interpretation in our daily lives. When we experience something, this is not seen to be a passive role, but one in which we as participants actively interpret and determine its significance as part of our account of the experience (Smith, 2019; Smith & Nizza, 2022). In IPA terms the researcher also plays this active role in interpreting the meaning and sense making described by participant. This researcher interpretation of a participants interpretation or understanding of their own experience is referred to as a "double hermeneutic" (Smith, 2024), which acknowledges that whilst trying to stay close to the original data, levels of interpretation is always inevitable, and that we as researchers cannot separate ourselves entirely from our experiences in a similar way that is also true for our participants (Pietkiewicz & Smith, 2012).

Idiography

The final principle of IPA is idiography, in other words an interest in the details that might make an experience unique and individual to a particular person, and in the level of detail and richness gathered (Smith et al., 2022). This principle was born from concerns that social sciences had become too nomothetic and only concerned with making more general or population-based predictions (Eatough & Smith 2017), with the likes of Allport (1940) and Harre (1979) arguing the importance of not only readdressing the balance between idiographic and nomothetic approaches, but also the importance of retaining idiographic understanding when building more generalised understandings or theories. Whilst idography can refer to the study of a single case, it can also mean moving to look across cases after idiographic interpretation (Smith et al., 2022), supporting Harre's (1979) suggestion of an idiographic base (Eatough & Smith 2017). IPA's attention to detail both in depth of detail, and for each individual involved also therefore lends itself to smaller, yet carefully considered sample sizes for exploration. This level of examination allows space for nuance possibly lost in other nomothetic approaches, whereby the impact of individual context is lost whilst using other qualitative or quantitative approaches (Smith & Nizza, 2022). In line with this idiographic underpinning, IPA with multiple participants attempts to describe patterns and points of divergence within an experience for a specific group of people at a specific time point, whilst also attending to the individual characteristics of this experience alongside it (Smith & Nizza, 2022).

Justification for Chosen Methodology

When considering the appropriateness of different methodologies, this was driven by the aims of my research question and epistemological stance. Whilst IPA was initially considered due to development for use within health psychology (Smith, 1996), there are several factors founded in its principles which made this a suitable data analysis method. For example, due to the interpretative nature of IPA and its theoretical underpinnings suggesting that we are trying to understand and interpret an experience as it has been understood and interpreted by our participants, this methodology was in line with a critical realist epistemology which also understood human experience as an interaction between the “real,” “actual,” and “empirical” level (Fletcher, 2017). Therefore, critical realism views certain events as real, yet interpreted through the subjective experience of the participant. Furthermore, IPA was chosen due to the ability to encapsulate in-depth details regarding experiences due to the idiographic nature of IPA (Smith et al., 2022).

Consultation with Experts by Experience

The role of Experts by experience (EbE) of a particular phenomenon is becoming more widely recognised for its importance within health and mental health research (Boivin et al., 2010). In the context of sexual and reproductive health, it has been suggested that this involvement helps to ensure the acceptability of the research design, facilitation of recruitment, and encourage inclusion from under-researched populations (García-Martín et al., 2020) with the gold standard being involvement from start to finish, and with meaningful remuneration (Perry & Mullins 2023). Research also suggested multiple benefits for EbE involvement in research such as, empowerment, increased confidence and skills, and a better understanding of their condition (Brett et al., 2014).

An Instagram page (@HPVMentalHealthResearch) was created to recruit a panel of six EbE to assist with designing and disseminating the research. Their involvement varied per person, depending on their availability and capabilities in terms of emotional labour. All EbE were offered a choice of meaningful remuneration. All six EbE provided feedback on the research question and methodology which encouraged me to broaden the scope of my research. I had initially thought to focus on aspects of shame, however hearing a variety of other experiences encouraged me to widen the scope to encompass all emotional experiences. Following this, an interview guide and demographic questions were developed, which were formally piloted with one EbE, as recommended by Smith and Nizza (2022), with a second EbE providing written feedback. Therefore, the guide was adapted to ensure the questions felt meaningful and sensitive. Finally, I plan to continue thinking together with my panel of EbE's when it comes to dissemination beyond publication.

In addition, during the early stages of the project, I consulted with Dr Ellen Daley, Professor and Senior Associate Dean for Research, Practice and Doctoral Training at the University of South Florida's College of Public Health. Dr Daley has done extensive work and research on the topic of hrHPV with several published studies in America already referenced (Daley et al., 2010; Daley et al., 2015; Daley et al., 2017; Perrin et al., 2006). Dr Daley's research and input supported the foundations for my research proposal. Originally, it was planned for Dr Daley to contribute to data analysis, but this was not possible due to difficulties with evolving commitments in her role.

Participants

Sampling

In line with the theoretical underpinnings of IPA, the sampling process was purposive and the research team subjectively selected members of the population who held expertise in the phenomenon of study. Therefore, the sample represented a somewhat homogenous group, and the results represented how the research question held significance for this group (Smith & Nizza, 2022). In line with research guidance for IPA studies on Clinical Doctorate programmes, I aimed to recruit six to eight participants (Turpin et al., 1997).

The study eligibility criteria are listed in Table 7 below. The study included cis-gender women, over the age of 18, either diagnosed with or who had tested positive for hrHPV via the NHS in the UK. To ensure homogeneity of experiences this research focussed specifically on cis-women. Women who had tested positive for lrHPV were not eligible to take part as often lrHPV is associated with physical symptoms of genital warts and can therefore come with a different burden and associated stigma (Jeynes et al., 2009). Women who had been diagnosed with cervical cancer or any other gynaecological illnesses that impacted their emotional response were not eligible to take part. This was explored explicitly as part of the screening interviews to understand any links or connections. Similarly, women who had received treatment for cell changes were not eligible, due to the additional emotional burden of an invasive procedure (Kola & Walsh, 2009). Finally, we excluded women who had received multiple positive results for hrHPV. This did not exclude women who had tested positive for hrHPV across multiple years as part of the same infection but excluded women who had received multiple positive results with a clear screening result in the middle. Firstly, this was to ensure we were capturing the impact of testing positive for the first time rather than the impact of a re-emerging diagnosis, secondly this was to ensure homogeneity of the experience being researched between women.

Recruitment strategy

Participants were recruited between September 2023 and May 2024. The study was advertised via social media (@HPVMentalHealthResearch) and Jo's Cervical Cancer Trust (see Appendix 1), a now closed organisation who provided cervical cancer awareness, education and support for individuals and families impacted by cervical cancer. The study was advertised on Jo's Trust's website and their “Jo's Voices” quarterly email newsletter to reach participants not using social media. Participants were not recruited via a specific NHS Trust as local procedures or staff might have impacted emotional response. In addition, due to possibility of shame or trauma induced by this experience, my connection as a researcher to the diagnosing or treating team may have deterred individuals from participation.

Due to significant interest in joining the EbE panel in January 2023 advertised via Instagram, I did not anticipate issues with recruitment, however recruitment for participants into the study was slow. I explored reasons behind this with participants and in supervision. It came to my attention towards the end that many participants

Table 7: An overview of the study's eligibility criteria

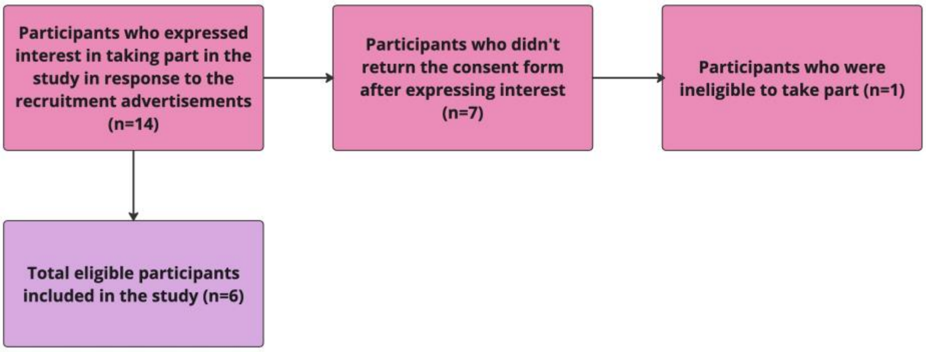
Inclusion criteria	Exclusion criteria
Cis-gender women	Trans-gender men
Received a diagnosis of hrHPV in the last 24 months and felt able to recall this experience in detail	Received a diagnosis of lrHPV
Received the diagnosis from the NHS in the UK.	Received a diagnosis of cervical cancer or any other gynaecological illness that had a direct and significant impact on the experience of hrHPV
Age 18+	Received treatment for abnormal cervical cells (e.g. Large loop excision of the transformation zone (LLETZ)).
	Received a diagnosis of hrHPV more than once (this did not apply to multiple results confirming one ongoing infection)

were not aware that they had tested positive for hrHPV, as their letter had not specified. It was only on exploring eligibility with participants that they realised their strain of HPV would be classed as high-risk as these are the strains currently tested for as part of their cervical screening programme (NHS, 2023b). It is therefore possible that this term confused some potential participants and deterred them from expressing interest.

It also came to my attention during recruitment that many of the words used in my recruitment strategy were flagged by Instagram as inappropriate and therefore shown to fewer people using the platform (Bodyform, n.d.). As a result, it is possible that less people were being shown the recruitment advert in September 2024 than in January 2024. Following these challenges, we decided to extend recruitment to include printed posters in community spaces. These were placed in local supermarkets, town halls, libraries and around the campus of the University of Hertfordshire. An ethical amendment was sought and approved and will be discussed in more detail below.

14 potential participants volunteered to take part, of these six participants were interviewed, one was deemed to be ineligible as she received the diagnosis outside of the UK and the remaining seven were lost to follow up (see Figure 2). Participants who expressed interest were contacted via email, if no response was received a follow up email was sent two weeks later. If no additional response was received, a closing email was sent two weeks later to inform potential participants we had closed their enquiry.

Figure 2: A flow diagram showing how participants were recruited



Participant Characteristics

The sample consisted of six women diagnosed with or tested positive for hrHPV via the NHS cervical screening programme. All names have been changed to protect the identity of participants. Participants could choose a pseudonym, or one was allocated. All participants were between 25-34 years old. five women identified as heterosexual and one identified as bisexual, suggesting a relatively heteronormative sample in terms of sexuality. Women had tested positive for hrHPV on either their first or second cervical screening. They were recruited from a range of locations across the UK. They all received their results via letter or via an online letter following a text notification. Several women (n=5) attended a follow-up Colcoscopy to check for Cervical intraepithelial neoplasia (CIN), meaning changes of the cells that line the cervix. Usually, CIN stage one or stage two changes will reverse by themselves once the body clears hrHPV, but removal is offered for the presence of CIN stage three cell changes. One woman had a biopsy of their cervix at Colcoscopy, but no further treatment was needed. Whilst this was not asked at screening, all women who took part happened to work in a healthcare role, but no women worked in roles caring for women who have tested positive for hrHPV at cervical screening. A summary of these demographics can be seen in Table 8.

Table 8: Participant demographics

Participant pseudonym	Age range	Ethnicity	Sexuality	hrHPV timeline	Result communicated	Other gynaecological diagnoses	Location of screening service	Format of results	Any follow up investigations?
Clara	25-34	White British	Heterosexual	Tested positive on her first cervical screening in 2022	HPV found and abnormal cell changes	None	South West	Letter	Colcoscopy and biopsy
Grace	25-34	Black British	Heterosexual	Tested positive on her first cervical screening in 2022	HPV found and abnormal cell changes	Endometriosis	North West	Letter	Colcoscopy
Penny Lane	25-34	Turkish	Heterosexual	Tested positive on her first cervical screening in 2022 and again in 2023	HPV found but no abnormal cell changes after first cervical screening. HPV found and abnormal cell changes at second screening.	None	North West	Letter	Colcoscopy

Participant pseudonym	Age range	Ethnicity	Sexuality	hrHPV timeline		Other gynaecological diagnoses	Location of screening service	Format of results	Any follow up investigations?
Lakshmi	25-34	European and South East Asian	Bisexual	Tested positive on her second cervical screening in 2022 and again in 2023	HPV found and abnormal cell changes	None	London	Text and Letter	Colcoscopy
Ruby	25-34	White British	Heterosexual	Tested positive on her first cervical screening in 2024	HPV found and abnormal cell changes	None	South East	Text and Letter	Colcoscopy
Taylor	25-34	White British	Heterosexual	Tested positive on her first cervical screening in 2022 and again in 2023	HPV found but no abnormal cell changes	None	East Midlands	Letter	None

Ethical Considerations

Ethical Approval

Ethical approval was sought and obtained from The University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (ECDA), Protocol numbers: LMS/PGR/UH/05448, aLMS/PGR/UH/05448(1) and aLMS/PGR/UH/05448(2). The second two protocol numbers represent two amendments submitted and approved by the Health, Science, Engineering and Technology ECDA. All certificates of approval can be found in the Appendix 2.

The first amendment, made in January 2024 included the following: changes to the wording of the inclusion criteria to provide clarity to potential participants, two new screening questions to help confirm participant eligibility, changes to advertisements to reflect the new wording, new social media posts to help boost engagement, and the recruitment of participants via posters (see Appendix 3).

The second amendment, made in April 2024 requested an extension to the recruitment period for data collection from the end of April 2024 to the end of June 2024 to allow me to collect enough participant data to meet the requirements for IPA (Smith & Nizza 2022).

Informed Consent

Once a participant expressed interest, they were issued an information sheet (Appendix 4) and a consent form (Appendix 5). If a participant reached out via direct message through Instagram, their email address was requested to send the information sheet and consent form. These documents discussed the purpose of the study, right to withdraw, the eligibility criteria for participation, the commitments required, the process of the research, disadvantages and benefits to participation, confidentiality, storage of data, ethical approval and who to contact in case of questions or complaints.

All consented participants were invited to a screening call (Appendix 6) to assess eligibility. Participants were asked to confirm a positive test result for hrHPV, about any additional health conditions (e.g. lrHPV, genital warts or cervical cancer), and asked if they attended any follow up tests and treatment for hrHPV. Demographic information was also collected. During the screening call participants were also offered an opportunity to ask any questions and verbal consent was checked again prior to proceeding. For some participants, eligibility was discussed prior to screening via direct message or email initially, but all questions were checked again as part of the screening call.

Confidentiality, Anonymity and Data Management

All data was password protected and stored on the General Data Protection Regulation (GDPR) (2016) compliant University of Hertfordshire (UH) One Drive in line with my ethical approval. Participants were informed that their participation and data would be kept confidential, and in some instances, details would be changed to protect their identities. Video recordings were only accessed by me during transcription, and all transcripts were anonymised and stored separately to the recordings. All consent forms, demographic information, video recordings and transcripts will be deleted upon completion of the research.

Looking After the Wellbeing of the Participants

During the interview introduction participants were reminded of their right to withdraw. Participants were also told they did not have to answer any questions they found too difficult, and that breaks during the interview could be accommodated. We spent time before the interview discussing how the participant might look after themselves. I also asked participants how they would like to refer to the experience we were discussing in terms of testing positive or being diagnosed and responses for this varied between participants.

After the interview, participants were offered the opportunity to ask the researcher questions. I also offered a space to reflect on the experience of the interview and took the opportunity to check-in on participants emotional wellbeing. Previous research suggests that the level of knowledge about hrHPV tends to be low within the general population (Kola-Palmer & Dhingra, 2020), however as I am not a medical expert, I, with my supervisory team decided not to provide medical information or advice to participants who displayed potentially inaccurate knowledge during the interviews. Instead, we directed all participants to the Jo’s Cervical Cancer Trust Website to seek support for unanswered questions or to find medically accurate information. Jo’s Trust was a now closed organisation who provided cervical cancer awareness, education and support for individuals and families impacted by cervical cancer. This resource was discussed verbally with all participants after the interview and was also included as part of the debrief sheet (Appendix 7). The debrief sheet also prompted participants to discuss any medical concerns with their GP and to reach out to local mental health services for emotional support should they require it.

Data Collection

Screening Call

The screening call was the first opportunity to build rapport with participants (Ranney et al., 2015) and eased them into the process of answering questions about their experiences. I used this opportunity to gather demographic information, but also contextual information about their experience of testing positive for hrHPV. Participants were asked about when this result was received, how this result was received and about any further testing or follow-up that they attended.

Interview Schedule

A semi-structured interview schedule was developed in line with previous research and feedback given by the panel of EbE's, who shared information about how their own experiences shaped their meanings (see Appendix 8). The interview started with more broad questions to allow participants to bring their own ideas and then narrowed at parts which might be of interest or require further probing.

As mentioned above, in line with recommendations for IPA research (Smith & Nizza, 2022), I completed a pilot interview with one of my EbE who felt the content of the interview covered what she expected. Another EbE provided written feedback via email. Amendments were made to include additional prompts around context of receiving the results, support offered by services and how someone might respond to a friend who experienced hrHPV. Originally, the demographic questions were asked during the interview but based on feedback from one EbE I removed the question about relationship status due to concerns this could lead someone to feel judged about how they had contracted hrHPV.

The interview schedule was based around eight key questions. Depending on participant experience we spent more or less time on each topic and moved through the questions flexibly. This was to support participants to bring topics which felt meaningful and important to their experience rather than opting for a more prescriptive set of topics. I included prompts to help guide follow up questions. This was not an exhaustive list of questions and not all questions were asked to each participant, especially if the questions were not relevant to that person's experience (e.g. partners reaction was not sought if the participant had already shared that they were not in a relationship during this time.) At the end I included an open-ended invitation for participants to bring any other topics.

Interview Procedure

Interviews were booked at the time of the screening call. Once the interview commenced participants consent was checked. Participants were informed when the video recording started and ended. The introduction was not recorded, nor was the debrief. All interviews took place remotely via Microsoft Teams. All interviews took place using both audio and video initially, but for one interview we had to turn the cameras off part way through due to an unstable internet connection. At the end of the interview, Microsoft Teams produced a recording and transcription to form the base of my final anonymised transcripts.

Whilst previously the gold-standard of qualitative research would favour in person interviews and previously there was less reliable access to remote platforms (Johnson et al., 2021), since the COVID-19 pandemic there has been a change in how we might choose to communicate. Despite this, research suggested that remote interviews could produce data as rich and in-depth as in-person interviews (Abramhs et al., 2015; Sturges & Hanrahan, 2004). Furthermore, whilst there can be additional barriers of technology excluding those without access, remote interviews did remove some barriers to access such as convenience and geography (Engward et al., 2022). To remove the barrier associated with technology access, I gave participants a choice of interview via Microsoft Teams or over the telephone. Furthermore, as I was trying to interview participants across the UK, rather than a subset of the population local to Hertfordshire, offering remote interviews followed logically.

All interviews were conducted in English. The interviews lasted between 53 minutes and 83 minutes (average=66 minutes). All participants were debriefed at the end of the interview and given an opportunity to ask questions. All participants were given a voucher worth £20 to compensate for their time however, to avoid undue inducement this was not advertised as part of the research (Resnik, 2015).

Data Analysis

The analysis was completed in line with the stages outlined by Smith et al, (2022). The process was iterative, and the researcher moved between the stages in a non-linear process, as the analysis developed and statements and themes were worked and then re-worked (Smith & Nizza, 2022). A summary of these steps can be seen in Table 9. Engaging with reflexivity was important to allow myself to attend to thoughts, feelings and positions as they arose. For example, I reflected that throughout this research I was often positioned as someone who held a greater or more accurate level of knowledge than my participants, perhaps due to my status as "researcher" or "interviewer," or maybe due to the research being completed as part of a Doctoral thesis. As a result, I often felt pulled into trying to give answers or provide reassurance to women with whom I could empathise. It was important for me throughout this process to engage in reflexivity in the form of a research diary, reflective discussions in supervision and bracketing interviews (Smith & Nizza, 2022).

Table 9: The six stages of data analysis (Smith & Nizza, 2022)

Stage	Process
One	Familiarised myself with the data and made exploratory notes. As the data was roughly transcribed by Microsoft Teams, I used this as a starting point for data immersion. I read and listened back to each transcript individually, whilst making corrections allowing familiarisation and immersion in that participants experience (Smith et al., 2022). Once the transcripts were complete and anonymised, I began to work through the transcripts one at a time making initial exploratory notes of my thoughts, reactions, questions and initial ideas. This was done by hand on paper, as is recommended for those new to the process of IPA (Smith & Nizza., 2022). These notes included attention to description, linguistics and conceptualisation.
Two	Formulated experiential statements. I then used my initial exploratory notes to formulate experiential statements to capture the essence of meaning from what the participant was saying. Smith & Nizza (2022, p. 39), describe experiential statements as "a concise summary of what emerges as important in the notes associated with the corresponding portion of the transcript." The analysis followed the recommended structure of three columns titled "experiential statement," "original transcript," and "exploratory notes," an example of which can be seen in Appendix 9.
Three	Connections and clustered experiential statements. In line with recommendations, experiential statements were typed up, printed, and cut into individual statements that could be moved around (Smith & Nizza., 2022). The essence of clustering was to make connections with statements, group similar statements together, and start to see how patterns could be determined within the data. Some experiential statements were discarded or combined, where they appeared often throughout the participants experiences or where it was perhaps better explained by a slightly different statement or deemed not adding new information to the idiographic understanding (Smith et al., 2022).

Four	Compiled the table of personal experiential themes. Clusters of experiential statements were then converted into a table of personal experiential themes (PETs) and listed alongside their corresponding quotes. As mentioned, this process was iterative, and although PETs were established prior to cross case analysis, the table of PETs was returned to throughout to refine and restructure where needed. An example of PETs can be seen in Appendix 10. Once the initial PETs were complete, these were reviewed by the primary supervisor to check for sensemaking and understanding of themes and ideas.
Five	Cross-case analysis and group experiential themes (GETs). Tables of personal experiential themes were printed and laid out where all participants could be reviewed together. Similarities, connections and points of divergence were identified across cases. Once an initial table of GETs was produced, these were reviewed in-depth alongside the primary supervisor, to check the understanding of certain themes and to shape the final structure of themes prior to write up. An example of the GETs and corresponding quotes can be seen in Appendix 11.
Six	The results write-up. The results were written up as GETs, with each containing two or more sub-themes. Due to the level of interpretation involved at every stage of the IPA process, there was inevitably more tweaks made during this final stage, with changes made to the final GETs as part of the final level of sense-making. These final interpretations were again reviewed and sense-checked with the primary supervisor.

Quality Assurance

To attend to quality assurance, this research was measured against Yardley's (2000) four principles for assessing quality in qualitative research.

Sensitivity to Context

Although I was reasonably well acquainted with the current evidence base prior to this research, I sought to deepen this understanding through the completion of the literature search and SLR. These activities helped me to become sensitive to the context which surrounds women when testing positive for hrHPV in the UK. Choosing to engage with participant experiences idiographically, as in line with IPA principles also helped me to develop my sensitivity to context through attending to nuance and individual aspects of each person's experience (Smith et al., 2022). Furthermore, working alongside EbE's throughout the process of this research helped to bring me closer to the impact of this experience and to help ensure the focus of the research felt relevant and sensitive to individuals who shared the phenomenon of study.

Commitment and Rigour

I was able to demonstrate commitment and rigour due to the immersive nature of IPA's methodology and by moving away from literal interpretation into a more analytic conceptual stance (Smith et al., 2022). This is evidenced by supporting extracts from the original transcripts in the appendix (Smith et al., 2022). Development of PETs and GETs were reviewed by the supervisory team for both sense-checking and collaboration purposes throughout analysis. I also engaged in regular reflective supervision and bracketing interviews with my supervisory team. As a team, we regularly discussed how aspects of our identities might be impacting what we bring to the project, and how we view the experiences of participants. Through these activities, I worked to interrogate and set aside my own assumptions, biases and experiences as far as possible when working to interpret my participants experiences (Smith et al., 2022).

Transparency and Coherence

I have demonstrated transparency and coherence in my detailed description of the research design and process throughout, and further evidenced this through carefully selected quotations and examples of analysis in the appendices. My positioning and motivation for the research has been disclosed honestly and clearly in the introductory chapter, further demonstrating a commitment to transparency. Throughout the process of this research I kept a reflective log, excerpts of which can be seen in Appendix 12. This was to ensure an accurate record of my thoughts, feelings and initial responses throughout the process, but particularly in response to participant interviews. This helped to support me through the process of bracketing my experiences as a woman receiving health-care support from those of my participants. Furthermore, throughout the analysis process I attended additional advanced methodology workshops not only to ensure adherence to IPA methodology but to engage in reflective discussions during interpretation.

Impact and Importance

When considering impact and importance, this has been carefully considered in line with previous research, and with theory. Significant clinical implications and suggestions for building on this research were also made to further this contribution. Aspects of this thesis were considered for publication to boost its impact, and other areas for possible dissemination will be discussed with the wider supervisory team and EbE's. By continuing this discussion with my supervisors and EbE this will help to ensure the impact is relevant for individuals whereby this research could hold the most significance, for example by thinking together of ways in which we can help this research to reach other individuals impacted by a positive hrHPV test result.

Chapter 3: Results

This chapter presents the findings using IPA methodology with the acknowledgement that these are an interpretation of participants experiences and are undoubtedly influenced by both my professional and personal context. The themes will be presented alongside corresponding quotes. Connecting with the different levels of context discussed in relation to the emotional response to testing positive for hrHPV brought by my participants during interview, the themes have been organised starting from the broadest level of context first, moving inwards towards more internal, individualised responses. These different layers of context were discussed at depth by all participants interviewed, which emphasised the importance of attending to emotional processes outside of those just described more individualistically. A summary of themes can be seen in Table 10 below.

Table 10: An overview of themes from the current study

Group Experiential Theme (GET)	Sub-theme
GET 1: The Narratives Held About hrHPV	1a. Conflicting Narratives of Stigma of hrHPV 1b. hrHPV as a Feminine Issue
GET 2: The Experiences of the Delivery of Services and Wider NHS Relationships	2a. An Un-human Experience 2b. Who Gets to Decide What We Know?
GET 3: The Relational Experience of hrHPV	3a. Connection and Disconnection 3b. Barriers & Conduits to Seeking Support 3c. Drawing on Experiences to Support Other People
GET 4: Cis-Women's Accounts of Testing Positive for hrHPV.	4a. The journey of Testing Positive for hrHPV 4b. The Impact of hrHPV on Self-Identity 4c. Sense of Powerlessness and Taking Back Control

Group Experiential Theme 1: The Narratives Held About hrHPV

These sub-themes spoke to broader societal narratives and contexts around the participants and their experience of testing positive or being diagnosed with hrHPV.

Subtheme 1a: Conflicting Narratives of Stigma of hrHPV

All women spoke to issues of hrHPV associated stigma, with the impact depending on their interpretation. For Taylor, the relationship between hrHPV and STIs felt unclear:

"I don't think it carries the stigma that like sexually transmitted diseases do, and I certainly don't feel about it, how I would feel if I tested positive for an STD" – Taylor

Taylor suggested she did not consider hrHPV to be an STI, and therefore it is without the additional burden of stigma. Perhaps by distancing hrHPV from other STIs this acted as protective against stigma. However, Taylor also recognized the difficulty of navigating opinions held by others, particularly men, and suggested they might fail to distinguish between hrHPV and other STIs. So, whilst Taylor was able to protect herself from stigma, she was still potentially worried about the impact of another's judgement on her emotional wellbeing:

"…I didn't want to tell anyone because maybe I still felt like there would be some stigma attached to having a virus, basically in your vagina. That wasn't something I wanted to share with anyone who wasn't like a friend or woman who understood..." - Taylor

Clara alluded to a similar uncertainty of hrHPV, asking herself "*do I have to disclose it,*" perhaps suggesting she felt some sort of "*responsibility*" to make the 'right' decision. Clara also described the "responsibility" as something to "carry," suggesting the burden of heaviness. This was perhaps linked to Clara's recollection of negative messages about hrHPV, as she recalled seeing "*somebody had been kind of outcast"* on the TV*.* This internal debate was possibly complicated by lack of discussion about hrHPV in wider society, with Clara suggesting this contributes to hrHPV being hidden. Less knowledge perhaps followed less discourse, and without opportunities for discourse, this had the potential to leave women to grapple with this uncertainty in isolation.

"…just felt like one of these kind of lesser spoken about ones and, like it didn't quite sit in a STI sense, but didn't sit elsewhere either …" – Clara

Clara tried to make sense of hrHPV as an STI by drawing comparisons with other STIs, and was left wondering whether hrHPV is more, or less stigmatised, based on predicted responses to Chlamydia:

"It's not quite, you know, Chlamydia or something where people laugh about it, if i don't know, if they're typically, men might laugh at it, if their mate gets chlamydia or something..." - Clara

Clara also reflected that despite stating *"it's nothing to be ashamed of"* that the experience had left her feeling *"a bit unclean,"* further suggesting the presence of inner turmoil around succumbing to stigma, despite beliefs which should have helped her to feel less impacted.

Ruby perhaps expressed something similar when sharing she "*did kind of like get myself out there a little bit more than I would knowing this now,*" suggesting that as hrHPV is less spoken about, Ruby was less aware of the associated risks. This also perhaps linked with Clara's position as it was possible Ruby is suggesting she only felt negatively, now that there had been a negative impact:

"it just made me think like a bit icky about like people that I'd slept with (laughs), but like not in a way towards them at all, just like icky about the experience and how I'm now having some, like I'm now going through something." – Ruby

This positioning could suggest internal debate about the impact of the link between hrHPV and sexual activity. This was further emphasized when Ruby suggested people might ask themselves "*oh what did I do for this to happen, like, and questioning like their actions and so I guess in some ways that probably means I was questioning them*." The reluctance of Ruby to state that she was questioning her actions, perhaps partially suggests trying to protect herself from impacts to her emotional wellbeing.

Lakshmi shared this inner turmoil, expressing *"stigma, shame, embarrassment"* whilst trying to manage conflicting feelings of wanting to reject this notion *"because I see myself as a feminist."* She also echoed Clara's sentiments of hrHPV as "*the slightly weird STI that no one really talks about…"* Perhaps feeling stigmatised came as a surprise to Lakshmi who usually described herself as *"out and proud."* This incongruence therefore perhaps also carried the additional burden of feeling frustrated.

"I felt worried, and a bit like potentially guilty, but also quite annoyed at the fact that I would feel guilty about something that I had zero control or knowledge over" – Lakshmi

Considering Lakshmi's worry and guilt in the context of sharing the diagnosis with her ex-partner, it is possible that his response of "*he probably heard, you know, HPV and thought STI and then thought, well, I've not had sex with anyone else, so it must be her*" contributed to a sense of internal self-blame. This is in contrast with a non-blaming response from her current partner perhaps helping her to see hrHPV as "*not something I feel, erm, ashamed of*" emphasising the importance of non-judgmental relationships in overcoming the impact of stigma.

Grace suggested the link between "*sex…being quite an uncomfortable topic for a lot of people*" and "*stigma*" to play a role in hrHPV being kept secret. She also alluded to the contribution of false narratives within society in people feeling ashamed and therefore not sharing their experiences:

"*… the things that people think, ok STIs means you're really promiscuous or HPV means that's you're really promiscuous."* – Grace

Whilst Grace was aware of the stigma associated with hrHPV, she did not feel stigmatised. She credited not only the openness of her upbringing, suggesting she learned that conversations about sexual and reproductive health are normal and healthy, but also "*my own, like educational erm, like background, in terms of like knowledge,"* in perhaps helping her to disprove some of the more stigmatising thoughts. It is possible that this combination has encouraged Grace to carry this sentiment into womanhood and protected her from some of the impact of stigma felt by other women

"…that aspect of my upbringing and the openness, and I guess ingraining that it's Ok to talk about these things and it's normal to talk about these things openly." – Grace

Similarly for Penny Lane, the stigma associated with hrHPV, was less of a concern despite her awareness of its impact on sexual relationships.

"In some cultures it's really big issue. With my friends, for example, they having issue with where I caught from who kinda questions. Not for us but a lot of people having that issue, I guess, in different cultures." – Penny Lane

For Penny Lane, she suggested that their cultures or perhaps their relationship had allowed her and her husband to navigate stigmatising concerns about hrHPV without this impacting their relationship, for example having infidelity concerns. In comparison, Penny Lane described their relationship as having a mutual understanding that hrHPV did not suggest dishonesty, signifying potential openness about their sexual history:

"…we didn't talk, erm think, you could cause that positive, I could cause that you get positive thing, because we know probably it could be from the first person we have sex with…" – Penny Lane

Sub-theme 1b: hrHPV as a Feminine Issue

This subtheme spoke to the impact of how hrHPV is positioned by services, and society. Several women were frustrated by the screening protocol and commented on the unfair divide of labour between men and women in managing the burden. For example, Lakshmi shared *"…it just like, yet another thing for women, or people with a cervix to deal with, and it just feels a bit shit (laughs),*" perhaps almost exasperatedly, representing how exhausting it can feel to hold this additional burden in relationships and services. She emphasized the role of services in perpetuating this by suggesting that female only testing *"…just lends itself to this idea that women are the ones who have to deal with this stuff, that we carry the burden…"* In addition, she alluded to conceptualization of hrHPV in this way, as contributing to a lack of understanding of the risk posed for men:

"…then I was like, oh, I didn't know men could get it, and he was like, yeah, they can, and so I was just like, oh, wow, I really don't know anything about this..." - Lakshmi

Similarly, Clara emphasized differences in responsibility between herself and her current partner, should he ever have another sexual partner:

"if I were to have another, another partner, it would be something that would be on my mind. Erm, but, yeah, I don't think it would be on his mind if he were to get another partner" – Clara

The contrast between the weight felt for herself compared to her boyfriend, due to the lack of male testing, meant he cannot test positive for hrHPV and therefore, can start a new relationship without having to consider the burden. Clara emphasised this by saying "*I don't think it's necessarily fair that the onus is on women,*" which when considered alongside her acknowledgement of the "*…you know it's linked to lots of different cancers. It's linked to cancer in, in men, like men in their genitals…"* suggested that Clara felt this heightened sense of responsibility not only for other women, but for men as well.

Grace held similar views, linked to differences in sexual education based on genitalia, and its contribution to how we conceptualise different sexual health conditions:

"…*then when it comes out and like I'm HPV positive and that maybe affects the both of us, I think that's why that, that friction comes from, because there is societal expectations that one group learned about one thing because that's what affects them..*." – Grace

Grace was alluding to the potentially negative impact for heterosexual relationships where only one person can access testing for hrHPV. She was frustrated by the sometimes unsupportive response women might receive from male partners but suggested a link to the socialisation of men's perspectives of women's health:

"I think like especially like Cis-Het males that will just be like, I don't need to know about periods because like doesn't affect me." – Grace

Penny Lane held contrasting views and approached this with concern for her husband's health without access to hrHPV screening:

"…it's pretty high risk of head and neck cancer, and yeah, males is more high risk on that. Why they are not getting screening, especially when it, erm, the legal partner having that..." – Penny Lane

Her frustration appeared to be linked other hrHPV related cancers. As she worked in head and neck cancer, an area with growing evidence linked to hrHPV, her worry was possibly driven by her context, and first-hand experience of its impact. It followed logically for Penny Lane that the feminization of hrHPV was frustrating and concerning, with a sense of injustice in the unfairness for men not being able to access screening for their health. This was emphasized by her repeated referral of risk to men throughout the interview:

"…head and neck ,erm, cancer types, esophageal, have a high risk when a person get HPV positive, and it's more common on males..." – Penny Lane

Group Experiential Theme 2: The Experiences of the Delivery of Services and Wider NHS Relationships

These sub-themes spoke to interactions between women and services, in terms of their structure, and the impact this had on testing positive for or being diagnosed with hrHPV.

Sub-theme 2a: An Un-human Experience

This sub-theme related to how experiences with the healthcare system influenced women's experiences. It spoke to the lack of human contact and how this contributed to feeling confused, anxious, abandoned, uncared for and, misled. All women interviewed received their test result via text, letter, or both. Many women spoke about the impact of receiving a result without containment from a healthcare professional (HCP) and highlighted the contrast to other NHS services.

Ruby felt that receiving results via text "*made it feel quite a lot worse*" and contributed to her distress because it "*felt quite uncaring I guess just to get it via text, like it's not important.*" This response alluded that Ruby felt unimportant, perhaps suggesting that the NHS does not care about her wellbeing. In addition, Ruby spoke about the inappropriateness of the context for receiving medical information, leaving her feeling unprepared, as it was *"a random Tuesday afternoon in the office and like I had patients that were coming like later that day,"* suggesting that Ruby perhaps found it difficult to balance being "*visibly upset*" in the context of her professional self. She went on to suggest that a letter would at least give time *"to prepare yourself."* Furthermore, perhaps for Ruby there was also something inherently cold and unpleasant about medical spaces, which happened to also be her workplace as she suggested:

"…I wasn't easily able to just like go home and be upset by myself like I knew I was in this, it's like in an industrial park it's really not a very nice place to be like, upset. I just wanted to like, be at home or with my mum, or like in bed …" – Ruby

Clara also expressed distress from receiving the results in writing, particularly in the context of cell changes, leaving her upset and without anyone to speak to for reassurance:

"*I was kind of, a bit worried. Well, very worried about, about that, because it's difficult when you haven't got a professional explaining it to you, when you've got just a letter to go by."* – Clara

She expressed feeling *"annoyed*" that she had been left without enough knowledge, and without access to "*a phone call to kind of explain."* She also reflected that there was something un-human about the process and shared that inaccessible medical words made *"…it feel like it's a more serious issue*," and expressed a desire for "*just more kind of human information, I guess. Information that you might share with a friend…"* This suggested that receiving the result by letter and its contents was perhaps a de-humanising experience. It is possible that when engaging with an empathetic clinician this can counteract the coldness associated with medicalization, with this experience leaving Clara thinking "*there was an* *assumption that, that you, kind of, you get this letter through, and you just get on with it"*

Lakshmi described the experience as "*a pretty shitty way to get a diagnosis*." She was particularly concerned about the lack of care and consideration for individual contexts due to hrHPV's link to cancer. For Lakshmi, the combination of a strong family history of cancer and receiving the results in an unsupported way left her with unanswered questions and perhaps a heightened fear of cancer. Lakshmi also shared feeling "*nervous to ask questions or to take up too much of their time*," which further emphasised possible feelings of unimportance. She went on to suggest that even just to "*hear someone's voice on the other end [of the phone] reassuring you… I just feel like it would have been really helpful."* Lakshmi also feared further de-humanisation during the process of Colcoscopy, and without anyone to consult was left to wonder *"…what if, you know, they say they're gonna do this thing and then I asked for anaesthetic, and they say no?"* This suggested that Lakshmi perhaps has had or is aware of previous experiences of withheld pain relief perhaps particularly in relation to women of colour. Furthermore, Lakshmi was shocked at the discrepancy between the level of care in comparison to receiving *"the most non-diagnosis of all time*" where she "*got a phone call,"* suggesting incongruence between the delivery of the results and the potential seriousness of the outcome.

In contrast Taylor initially felt reassured, particularly due to the description of a cold analogy which "*made it sound like it's a very fleeting thing, it comes and goes really doesn't mean much*" and described her response as she "*carried on my life*." Usually when a test result suggests something serious, women might expect a telephone call or an appointment, so it's possible a letter felt reassuring. This is perhaps emphasized by Taylor stating, "*The NHS is quite reliable in terms of reaching out to people as and when they need to."* However, after testing positive again her reassurance began to waiver:

"I got my results as a letter in the post after my second smear and you can't, so no one's on the phone or in an appointment giving you that information and giving you an opportunity to ask questions." - Taylor

After realising she was still testing positive, she felt uncertainty at having *"no one to be directed to, and [that] GPs are impossible to get hold of,"* perhaps suggesting a sense of lost faith or trust in the system. Furthermore, without opportunity to seek reassurance from a HCP she was left frustrated by "*the lack of acknowledgement that this could have any impact on somebody*" again suggesting she felt un-cared for. Taylor goes on to say "*I would expect, or I would hope, there to be some opportunity to ask those, ask someone with some knowledge the questions that you have*" with the correction to "*I would hope"* perhaps further emphasising a shift in her expectations of care.

Penny Lane struggled to believe the letter and remained sceptical about the level of risk presented. In contrast, she desired more *"percentages"* and *"risk possibilities"* and perceived the letters as *"so optimistic."* This is possibly a reflection on her profession in oncology and perhaps she felt safer to think of risk in terms of statistics. Interestingly, despite this desire for potentially more medicalised information, she still felt that interacting with a HCP would have given her reassurance, suggesting she would still like to feel cared for. It is possible that this interaction would have helped her to feel less like a HCP and more like a patient.

"*Someone should have that universal knowledge and they could call me and check in, how I understand the letter*." – Penny Lane

Sub-theme 2b: Who Gets to Decide What We Know?

This sub-theme spoke to the impact of knowledge, or limited knowledge, and emphasised the impact of this being withheld. For example, Grace reflected that her educational knowledge helped her to feel reassured, as she understood the implications and what would happen next. This not only removed uncertainty, but also reassured her that there were not significant health implications for her at this stage:

"…erm the knowledge that I had about the process of testing, erm and like the process of colposcopy and stuff like that [made it a lot more manageable]" – Grace

Grace acknowledged the rarity of her knowledge, as she noted the potential test results were not explained during screening, suggesting that "*it's not blanket information that healthcare professionals have to tell patients."* Her level of knowledge, and pragmatic response to hrHPV perhaps also impacted her identity as a patient. As Grace held more knowledge, maybe she moved into the position of HCP. This is supported by her statement that other women need "*a proper explanation…before the results are even given.*" Grace went on to say that as "*soon as that word, terminology, Cancer, is involved I think people do just shut off*" and in this statement she was possibly speaking from her experience as a HCP.

This lack of transparency, or sense of withheld information was a common theme for some women. For Penny Lane she felt unprepared, perhaps alluding that if she were aware of the prevalence of hrHPV, she may have been less shocked:

"…after get the result I saw it's 90% every woman gets HPV. I thought, nobody tells you is gonna be possibly positive." - Penny Lane

She also described feeling *"fooled"* as the strain of HPV was withheld, perhaps therefore contributing to the intensity of her response at her second screening. Perhaps Penny Lane felt less prepared for the perceived progression of additional cell changes when she was not aware the strain of HPV was linked to cervical cancer. This lack of transparency was perhaps particularly frustrating for Penny Lane because in Turkey "*they are giving all results at when it's the finalized all bloods, all MRIs, scans, everything,"* in contrast to the NHS where Penny Lane perhaps felt her questions would not be answered, with the repetition of "*I don't know*" possibly suggesting a loss of faith in the system:

"I even don't know if I get back to them and ask is it high risk or low risk are they gonna say me which kind of HPV I have? I don't know." – Penny Lane

The similarities described between hrHPV, and a common cold seemed important to Taylor, perhaps because it highlighted it's prevalence or suggested that it is nothing serious, but after a second result she began to question this metaphor and it's helpfulness.

"you said it's like a cold, a cold goes after four or five days. It's not gone after a year. Like how, how are you making sense of that, Because that's not what, that's not the information you've given me" - Taylor

Although Taylor alluded to feeling misled, she did not seem to think this was deliberate, however she was clearly frustrated and remained confused without answers as to why her experience was seemingly different.

"I'm not calling them liars, I'm sure in many cases it can be a virus that comes and goes in a short period of time, but I don't really care because that's not my experience." – Taylor

The longer Taylor waited for answers, the more she questioned the protocols, leading to questions not just about the accuracy of information, but also about the HPV vaccination protocol. In the UK context where polio is very rare and hrHPV is very common, by comparing the HPV vaccination to the Polio vaccination, Taylor was possibly demonstrating her level of confusion to learn that she could still contract hrHPV. It suggested that Taylor felt misled in believing she should not be concerned about hrHPV. Similarly to Penny Lane, it was possible that Taylor was also beginning to lose trust in the NHS, especially in the context of multiple positive hrHPV results.

"…well, I guess nothing's ever 100%, but my understanding is that once I've had the polio vaccine, you can't get polio…" - Taylor

Ruby's experience of information being withheld was short lived, but still contributed to her experience. She expressed initial confusion when receiving a text inviting her for additional testing due to "*changes which have been found in your cervix*" with limited explanation. Ruby described feeling "*left in the dark,*" perhaps suggesting that she would have expected more information in the context of an abnormal result:

"…a almost dia- like it wasn't even a diagnosis, that kind of in some ways made it worse that I knew there was something going on, but they didn't fully give all the information" - Ruby

Perhaps Ruby's fear was driven by the uncertainty of not knowing exactly what was wrong, leaving her to imagine outcomes scarier than reality. It is possible that this was intensified by Ruby's level of knowledge, as she described herself as "*reasonably clued up*" and described that she "*sort of knew what it could be erm, but i didn't have 100% confidence.*" Perhaps having some knowledge of links between abnormal cervical screening results and possibility of cancer gave Ruby a specific outcome of concern, as Ruby stated she "*just went into very much, you know, thinking the worst.*"

Early in the interview Lakshmi shared "*just for the record, it didn't state whether it was high risk or not at the time on that letter. I only got that later on*," suggesting this felt important to share. The experience left her questioning the system's set-up and suggesting that the NHS is assuming what patients need to know. Whilst the intention behind this might be to protect from worry, in Lakshmi's case this led to more worry. When she reflected on her current knowledge, she thought having this information earlier could perhaps have prevented the experience from feeling as distressing.

"I could have gotten information two years ago and that would have just been super helpful. And so it's, it's, it's so silly that you're then leaving people with this anxiety and kind of this assumption, they don't need to know certain information…" – Lakshmi

Group Experiential Theme 3: The Relational Experience of hrHPV

These sub-themes spoke to the interactions that women had with other people in the context of testing positive for or being diagnosed with hrHPV.

Sub-theme 3a: Connection and Disconnection

This sub-theme spoke to the varying experience of feeling connected and disconnected through the experience of sharing the results, leaving women feeling both isolated or united.

Connection felt important for Ruby as she reflected on the helpfulness of being able to speak to her Mum after receiving her results, sharing that "*hearing her* *voice in general, that was probably like what I needed.*" This suggested she needed to feel comforted, perhaps also by someone who might be able to empathise based on shared experiences of accessing women's healthcare. Ruby was not necessarily looking for answers, but wanted to feel connected:

"…she was just like, I don't really know what it means (laughs), but erm, so she wasn't particularly helpful in that sense. It's just comforting to hear someone that you know…" - Ruby

This bond was of relevance for Ruby in the context of her Mum's recent difficulties with mental health. Testing positive for hrHPV perhaps presented Ruby with an opportunity to be able to move back into the role of child and for Mum to move back into the role of caregiver, emphasising the importance not only for Ruby, but perhaps also for her Mum.

"…that's quite like a bonding experience for the two of us [mum and i], because it is something that she genuinely can help me with and feel like useful for, which is something that she's struggled with ever since [she experienced psychosis]." – Ruby

Ruby also described the process of sharing the results as a *"coping mechanism,"* because it stopped her from "*overthink[ing] it and go[ing] into a spiral.*" This suggested a grounding effect in the act of explaining something when she held a position of knowledge, perhaps by distancing herself from some of the emotion.

For Clara a sense of connection was difficult to access initially, and she described conversations as "*quite fear driven conversations, quite anxiety fuelled, and a lot of me kind of, just seeking reassurance*." She alluded to seeking responses from others in the hopes that they would be able to reassure her. It suggests that this was a conversation Clara might have had several times, before she started to receive validating or reassuring responses from those with shared experiences. This perhaps suggested that Clara was looking for someone to help her to feel less alone in the experience.

"…I told a couple of people because they were, kind of, worried why I was upset and somebody kind of pulled me aside and was like I had that too, it's fine, it's cleared up, we're all good, and that was definitely reassuring." - Clara

Grace's experience spoke to a simultaneous sense of connection and disconnection. After telling her Mum, Grace described a sense of "*empathy*" and "*that feeling you get when you share an experience with someone*" suggesting a perhaps deepened connection of shared experiences. However, she also acknowledged that this could cause heightened anxiety if the experience was negative. Whilst Grace felt somewhat reassured to know "*someone that's been through it and tested positive, had the [LLETz] procedure and is fine*," she was also anxious to hear Mum described the procedure as "*so painful."* This anxiety was possibly intensified by the level of trust in their relationship, leading Grace to hold this opinion in high regard.

"Erm I think as well maybe some of the anxiety that I had towards the procedure, erm that [her mums experiences] probably contributed…" - Grace

Grace also spoke to connection felt when sharing the positive test result with her boyfriend, despite some Initial "niggling" concerns that her boyfriend might react negatively. This perhaps highlighted that these sorts of concerns can happen to anyone, even a medical student with a higher than average knowledge of hrHPV. She emphasised that the conversation felt supportive as they were able to reach conclusions together, showing shared decision making through the phrase *"we both came to the conclusion that, erm it would probably clear and it wasn't too much to worry about."* For Grace, this experience helped strengthened their bond and encouraged her to feel supported in her vulnerability.

"*Having someone that responds in that way to that topic is, erm I think it helps to build like, build trust and erm like supports like that open communication."* - Grace

Lakshmi's experience also emphasised the importance of open-mindedness in feeling connected when sharing the result with a sexual partner. Her initial experiences were full of tension, frustration and possible resentment as she described it as "*quite an awkward period of time, I suppose, especially since I was, like, freaking out about my own health and like the potential of having, erm, cance*r." A sense of disconnection was emphasized by Lakshmi's repeated use of the pronoun "*I"* rather than *"we"* when describing their interactions, supported by statements such as "*I feel like figuring out together is a bit strong because I think I* *was trying to figure it out.”* This suggested that when Lakshmi was seeking support from her boyfriend, she was perhaps left feeling abandoned, with attempts to re-engage him in a supporting role ending in disagreements:

“…I like had to go and do that research about the Colcoscopy and kind of said to him, oh I'm nervous about this and I think we then had an argument about whether there were nerve endings in the cervix or not.” – Lakshimi

She also described a sense of distrust and blame from her ex-partner, which perhaps left her frustrated as she describes having “*zero control or knowledge*” over contracting hrHPV. Lakshmi perhaps also felt judged for her sexual history, as she was automatically assumed to be to blame. However, Lakshmi also alluded to preparing herself ahead of the conversation, perhaps suggesting she pre-empted this positioning of how sexuality can be perceived in women.

“He'd never had penetrative sex before me. I had had plenty of penetrative sex before him, and so there was a bit of that tension where he was a bit like ohh well, you know, you've probably had it and probably given it to me now, and I was like well, that's not necessarily the case because you had other types of sex with other people before, and like, I, you know, had done a bit of research” – Lakshmi

Penny Lane experienced both connection and disconnection when sharing hrHPV with friends. Prior to her second positive test result, Penny Lane’s friend shared her experience of cell removal treatment and her concerns about the implications of this. Similarly to Grace, Penny Lane alluded to how this experience intensified her anxiety in relation to her own result which perhaps also left her feeing disconnected. This is perhaps supported by Penny Lane later seeking emotional support from a “*different*” friend than the one with whom she held that shared experience.

“…she was going through the same process before just I received the same result with her, just, her, hearing that experience, erm from another one, without knowing my results, it’s just probably frightened me more when I received mine.” – Penny Lane

Instead, Penny Lane opted to speak with a friend who worked in Oncology, who she predicted would “*understand[s] me and she share my, erm fear*” but without having to hear more about the experiences of cell removal treatment. It is also possible that Penny Lane felt she could connect with this friend and might feel more comforted, due to her profession as a Psychologist. Ultimately this experience of sharing her results with someone different, perhaps represented her seeking empathy and validation to lessen the emotional impact.

"…when you share it, it's hurting less. I hope so." – Penny Lane

For Taylor, the idea of seeking emotional support or connection did not resonate and she stated that she "*wasn't telling people. I wasn't, I wasn't sort of seeking emotional support."* Objectively, Taylor's approach after testing positive a second time did not seem to change. However, the way in which this event was described perhaps suggests a slight sense of seeking reassurance when she shared her confusion about the result.

"*I might have said it again to my mum. Oh, I've got this result again, like a bit confused about why It would be positive again when it's supposed to just disappear so quickly..*." – Taylor

This was perhaps supported by Taylor's later comment that "*it wasn't even till I saw about your research that I thought, oh, are there are other people going through this and actually like, feel some kind of way about it."* This statement was suggestive that there was part of Taylor that perhaps felt slightly isolated by the experience.

Sub-theme 3b: Barriers & Conduits to Seeking Support

This sub-theme spoke to factors which made sharing feel easier or more difficult. Some women identified both barriers and conduits to sharing their results, whereas others only spoke to one. For example, Lakshmi experienced both and identified one of the biggest barriers as the impact of cumulative stresses when testing positive. It is possible that Lakshmi felt she could not allow herself to properly connect with the experience out of fear that this might cause overwhelm. There was perhaps a fear that if she speaks to the experience, this would bring about emotions that were too difficult to manage.

"I was just like, OK, I just need to like, hold this togeth.... hold myself together essentially, and I can't have this conversation with that many people because I just won't be able to manage the like, the whole thing anymore"- Lakshmi

Lakshmi also spoke about both anticipated and received responses to sharing as barriers. For example, she hesitated when sharing with her Mum as she predicted that her Mum would feel anxious. It might be understandable for a Mum to feel worried in this context, but for Lakshmi having to be emotionally strong for her Mum was potentially emotionally draining, as she described "*reassure[ing] her that having HPV doesn't mean that you have cervical cancer and kind of did the whole like, reassuring someone else, even though you're not reassured*." This suggested possible frustration that Lakshmi desired reassurance, but instead ending up giving this to others. Lakshmi also received judgement when she had initially shared the results with others which was also perceived as a barrier:

"*a couple of people said to me, like, oh, did you not get the vaccine when you were younger, and I was like no, erm, and, and then felt really stupid for it." -* Lakshmi

The judgement for Lakshmi's vaccination choices left her feeling ashamed and ultimately disconnected. The sense of judgement felt in this context perhaps indicated a sense of implied blame, which was perhaps supported by Lakshmi trying to explain the context for her decision during the interview, perhaps out of fear that I would make similar judgements:

"…I just remember being like, ooh I'm old enough now to make my own health related decisions, and it's such a new vaccine, I don't know anything about it…" - Lakshmi

However, Lakshmi also spoke to the power of solidarity, when eventually she received validation, rather than judgement. This prompted reflection on previous experiences of sharing and reminded her of how this can build deeper connections, in turn helping her to feel less isolated.

"…I probably just told one or two additional friends, and one of them was like, oh, my God, yeah, me too, and then on that basis, it just reminded me of other times in my life when I've shared information about my sexual history, kind of experiences

of sexual violence, things like that, where like suddenly people are like, Oh my God, me too, me too. Which is, you know, super depressing, in those contexts, but also incredibly validating…" - Lakshmi

Penny Lane feared burdening others with emotional distress associated with cancer as she stated, "*It's not something, I don't want to share unless it's become a real thing*," suggesting a hesitancy to worry her family about something which might never come to fruition. Penny lane was keen to explore all possible avenues, before turning to her family for emotional support, for example she said, "*I could avoid with removal, with healthy lifestyle*," further emphasising a desire to manage without their knowledge. She went on to suggest *"I don't know, what I'm gonna do, if it's gonna be the real thing,"* alluding that she would even consider keeping a real diagnosis of cancer private. The extent of Penny Lane's avoidance was perhaps indicative of the level of cancer related family trauma, and suggested strong narratives linked to cancer making the experience too unbearable for her family. This is supported by Penny Lane sharing the following story about her Grandmother:

"*We have a trauma with our uh, my grandmother, my mum's mom. Erm, she had the diagnosis, just before one and a half months ago, from her death. So it's something affected us pretty hard*." – Penny Lane

Clara was perhaps also concerned about the responses of others, particularly in the context of seeking professional emotional support. It seems Clara felt hrHPV was unworthy of professional support despite her "*really strong fear."* She seemed to feel her experience did not meet sufficiently serious enough criteria to justify accessing services aimed at individuals struggling in context of cancer. Perhaps Clara feared she would be turned away by services and her emotional response invalidated:

"I didn't feel like I could ring up kind of, cancer UK or, or, whoever, or Macmillan and be like, hey, I've got, you know, abnormal cells and HPV, give me support when there's people out there who actually did have a diagnosis of cancer." – Clara

Furthermore, it was possible that Clara was trying to maintain a sense of calm to reassure herself, as she shared that "*It hadn't been confirmed as anything at that* *point*" and "*even though I was really scared, but I didn't have anything to be scared about at that point in time.*" This was perhaps supported by Clara's later reflection of "*I did think, you know, I could be overreacting, because I tend to do that when it comes to stuff like this anyway*" which suggested that perhaps Clara had been told she has overreacted in the past and therefore was concerned of repeating this response.

For Ruby, a sense of safety in her relationships was important for sharing, as she reflected that the length and "type of relationship" with her partner supported her to feel safer, and even though she expected "*that he'd want me to, to explain*" she anticipated that they would navigate the concerns together. Ruby was alluding to trust possibly built over years as she went on to share that "*if I it was someone I was newly dating, I probably wouldn't have felt the same*." A sense of safety was also present in her relationship with her Mum, as she described her Mum understanding to be based on her own experiences of invasive procedures such those sometimes associated with childbirth. These shared experiences signalled to Ruby that she would be supported and understood.

"…especially mums because they've had even more invasive stuff than that, like if they've given birth, so erm, yeah. Like i really think that was why she's, was the easier, the, the best person for me to speak to at the time…" - Ruby

Grace described being quite open, stating "*if anyone asked me, I would be happy to, to say…I would share that experience like it doesn't really matter*," suggesting a relaxed attitude to sharing. When considering what shaped Grace's response, she talked about her experience growing up with a Mum who was "*quite open about like, obviously HPV testing*" and described the nature of sharing this kind of information to be "*all that I've known growing u*p." Grace reflected that "*as a group erm, black Caribbean people are not the most open with sexual reproductive health*" but that watching this modelled by Mum over the years contributed to Grace's ability to be open, perhaps in turn to try to model that same openness for others.

Sub-theme 3c: Drawing on Experiences to Support Other People

This sub-theme described how some women supported others by drawing on their experiences. Grace for example, emphasised sharing her experience as part of her sense making, as she referenced the “*educational perspective*” she considered throughout the process. From a social justice perspective, Grace seemed to recognise inequalities within healthcare, as well as “*not a lot of education*,” and perhaps understood the privilege of holding her level of medical knowledge alongside the openness of her upbringing in combating feelings of distress related to hrHPV.

“I feel like horror stories stop people from going to their smears, erm and I feel like there's obviously groups as well, like, like trans men won't go for smears because of, sort of, not knowing about the process and the, the discrimination that they face in healthcare. So I think I just wanted to, contribute to a, sort of, unbiased and more erm jargon free educational resource, that's easily accessible.” – Grace

By connecting with others and sharing her experience, Grace was hoping not only to demystify the process, but also perhaps trying to close the gap between HCPs and patients, in turn providing her results with a sense of purpose and meaning.

“I made a, erm, like I made a video for going for my smear, getting my results, and explaining to people what those results mean, and that it doesn't mean that you've got cervical...” - Grace

This was also perhaps linked to Grace’s strong identity as a HCP in that she took pride in caring for others, as she shared the additional layer of support she hopes to offer both personally and professionally:

“I was able to actually say like how it felt as opposed to like, this is what I know from reading or from seeing other people going through it. So I think it, I guess added to the support that I could give to my friend and maybe will be able to give to other people going forward…” - Grace

Clara also alluded to wanting to support others and suggested that being transparent about distressing experiences might help support someone else in a similar situation. Like Grace, perhaps this too was linked to Clara's aspiration to pursue a career in healthcare.

"*I'm the kind of person where like it's better to share it than not, because somebody might have been through the same. Somebody might go through the same in a year or so, and will think, oh Ok that, actually somebody else went through that…"* – Clara

Furthermore, in this specific context, it is possible that Clara wanted to provide support to others that she did not have when initially testing positive. Perhaps due to her own experience, Clara therefore wanted to protect others from similar experiences of isolation. This was perhaps supported by Clara's statement of sympathy for her past self:

"I feel bit sorry for her [past self] that she didn't have that information and was that scared, erm and didn't have anyone to kind of say like, oh don't fret it's fine…" – Clara

Taylor felt it was important to use her experience to prompt someone close to her to engage in more health-conscious behaviours. She reflected her awareness of narratives held in society about cervical screening and thought that only hearing negative experiences was likely to contribute to non-attendance.

"I think I was well aware that sort of the fear of how uncomfortable it is was one of them. And when you've not gone through something yourself, you only ever, all you have to go off is what other people say about it..." - Taylor

However, she also shared that she "*never found it as bad as what people made it out to be*," suggesting surprise and perhaps frustration at the negative associations linked to screening. It was possible that Taylor therefore wanted to contribute to a more neutral narrative to encourage others to attend.

"'cause I told her she's, I told my friend you need to go and get your smear, because she's the kind of person that doesn't ever go to the doctors and will put things off for months and months and months and months.." - Taylor

Group Experiential Theme 4: Cis-Women’s Accounts of Testing Positive for hrHPV.

These sub-themes spoke to the individualised aspects of the experience in the context of testing positive for or being diagnosed with hrHPV.

Sub-theme 4a: The journey of Testing Positive for hrHPV

This sub-theme spoke to the variety of responses including fear, surprise, relief, optimism, and sadness. For some, testing positive for hrHPV came as a shock for several reasons such as, previously normal cervical screening results or feeling protected by a long-term monogamous relationship, whereas others were perhaps expecting a positive test result. Some women expressed fear or anxiety about their health, their partner’s health, or in relation to further medical investigation. Some also described a sense of regret and grief.

Lakshmi initially expressed “*feeling quite shocked, I suppose because the first time around when I'd had a smear test, nothing of the sort had happened*,” suggesting that a previous negative result felt protective. In addition, perhaps Lakshmi felt reassured as the examination itself had felt so relaxed:

“…*this nurse was so lovely and chatty that I just like, was completely relaxed. It was over before I knew it and just felt absolutely fine*…” – Lakshmi

Following this, Lakshmi then started to experience fear and worry. After “…*having Googled what a colposcopy was I freaked out even more because I was like, oh my God, it’s gonna be really painful,”* with the description perhaps causing intimidation. Lakshmi also experienced an intense fear of being diagnosed with cancer, and she described this fear to “*loom[s] quite large*” particularly in her context of “*quite a significant history of cancer.*” Lakshmi gave the sense that this family history contributed to her fearful response of “*oh my God, abnormal cells, that means cancer, right?”* This could also be linked to the terminology used, as the phrase abnormal cells is not common and can often be associated with cancer. Lakshmi also started to feel “*concerned*” that she had “*given it to my ex-partner*,” perhaps suggesting potential feelings of guilt, responsibility or self-blame as her statement suggested an assumption that she would have had it first. She expressed regret associated with her vaccination choice and was left perhaps feeling frustrated that she was not encouraged to receive the vaccination by her Mum, and at herself for not considering the future implications.

"…I just think now, like God, why didn't like my mum just make the decision [for me to be vaccinated] for me." – Lakshmi

Lakshmi shared that over time she was able to carry on with her life, without it causing regular distress, however this was short lived between screening appointments, perhaps because this was a reminder that her body had been unable to clear the virus.

"*I actually completely forgot about it, I got tested again last year and it was positive again, which was actually quite scary…*" - Lakshmi

Penny Lane described initially feeling "*shocked because it was my first smear test*," suggesting perhaps an association of cancer with someone older than that at first cervical screening. Perhaps this also was not in line with her expectations for the results, as she described "*probably I even forget the smear test, when I'm waiting*," and attributed this reassurance to "*I've been married for three years, and that's mean I am, erm, I have a single, erm, partner, erm for sex for a long time*." Penny Lane was perhaps suggesting feeling protected by her monogamous relationship, with this suggesting lower risk. She also went on to express fear and anxiety for her husband's health, going so far as "*it's my first thing, to think about my husband*" rather than herself. Her concern was expressed with an awareness of no access to screening for males, perhaps suggesting she was at least reassured by access to her own healthcare. This concern may also be intensified by knowledge regarding the impact of hrHPV in men, as Penny Lane shared that "*working on head and neck cancers…it's all about HPV positive,*" which might have led to an increased sense of fear, due to the heavy presence of hrHPV related cancer in her daily life for men.

"*…all that awareness [of hrHPV in men], that was awful. I hope in their, erm his metabolism better than mine. I'm just, I can only hope*." – Penny Lane

Although Penny Lane acknowledged "*I'm still feeling that when I know more, I'm feeling more comfortable*," she also felt that she should "*not know, what I know about the, erm, results of having high risk"* and alluded to the impact of high knowledge and anxiety in managing the impact of hrHPV. She also alluded to the time it takes to process the result, perhaps suggesting that she needs to move away from those initial stages of shock and distress to properly process the results, but also the complexities of distress and how this is processed in a non-linear way.

"*The second letter is just been received a couple of weeks ago, so I'm still not sure how I, erm, how I'm getting respond to that."* – Penny Lane

For Clara, minor anxiety started prior to receiving the results, as she described being "*a little bit worried towards, towards the end of waiting for my results because I'd started having some bleeding*." Prior to this she shared "*the first one came back with no kind of, issues*," alluding to a sense of reassurance in receiving a previously normal cervical screening result, perhaps allowing Clara to continue *"living in that ignorance of like it, it'll come back fine*," despite the presence of these symptoms. It was perhaps this reassurance, or sense of avoidance that then contributed to the results feeling shocking. In addition, perhaps Clara was also weighing up her perceived level of risk in the context of her previous health-checking behaviours and her current relationship status:

"…*I've been quite sensible with my kind of sexual health and making like, going to checks and things like that between partners and I've been with a long-term partner at that point…"* - Clara

For Clara, this "*state of shock*" seemed closely linked with cell changes found in her sample. She alluded to feeling less concerned about hrHPV because the implications for cell changes felt more concerning in their link to cancer. This was perhaps supported by Clara sharing "*I don't think I knew that they would test for HPV either*," suggesting she was also unaware that the process included a test for hrHPV.

"*I was just in a bit of a state of shock, I think. Erm, less about the HPV diagnosis I guess, because I didn't really know what that meant and what high risk HPV really means, and I don't know if it really said it on the letter. I think it mainly said about the abnormal cell changes*." – Clara

This fear of a potential cancer diagnosis was reflected in Clara’s statement that she “*started to get a bit emotional, because my head went straight to like, I've got cancer*,” and then she described “*spending the weekend crying*.” This intense response perhaps represented Clara’s level of belief in the prediction she would be diagnosed with cancer. This was perhaps also linked with a sense of regret, described as “*a kind of wish of wanting to go back and redo things thinking, you know, I haven't, I haven’t done enough with my 20s*,” alluding to Clara’s time feeling more precious. This phrase could also suggest Clara feared that she would not have enough time to change this, perhaps also suggesting concern that the cancer will be untreatable.

Clara’s emotional state improved over time after testing positive, but perhaps this was linked to her context. She reflected that she “*overreacted*” initially, based on “*information I know now*”, suggesting that at the time, her response felt valid and justified. This was perhaps supported by Clara sharing she was “*annoyed*” that she did not have access to reassuring information in the first instance. In addition, as Clara’s prognosis improved, this perhaps allowed her to feel less worried:

“I think it was so long ago, and since then I've had information that it looks like it's getting better, so we’re on a kind of, good path.” – Clara

Taylor did not anticipate feeling concerned, even if she were to test positive for hrHPV. She shared that she “*didn't really care. I, I really didn't think about it*,” and expressed only being concerned if they had “*checked the cells and they were abnormal, and they tested more and I had cancer*.” Her understanding of hrHPV was that it “*doesn't seem to mean an awful lot*” and her estimate of level of risk from cervical cancer was low, regardless of testing positive.

“The chances of that are quite small, and I think I'm generally quite a pragmatic person, so I just thought the chances of me actually having cancer right now at age 24 and a half are pretty slim, so I'm probably fine.” – Taylor

Taylor continued to express a “*pragmatic*” response to her results, despite “*in the very moment*” feeling “*minor panic*.” The comparisons made between hrHPV and a common cold reassured Taylor and left her feeling unconcerned. Perhaps this was reassuring because the comparison suggested that hrHPV was temporary. In addition, perhaps a cold felt familiar and in turn reassuring, as supported by Taylor's comment of "*it's something we all experience*." A familiar experience perhaps came with certainty, suggesting she might feel reassured. As described in her initial expectations, perhaps she was also reassured to learn that they had not found any cell changes.

"*…when I read the rest of the information and, and sort of saw those comparisons to other more common viruses as well, I stopped panicking quite quickly and was able to just think you know, it's not, not, think too much of it*" - Taylor

This comparison felt less helpful after Taylor tested positive a second time, and perhaps contributed to her surprise, worry and frustration. From Taylor's perspective, for hrHPV to hold similarities to a cold she should no longer be testing positive:

"*I was really surprised 'cause I thought this virus would have gone by now, but it hasn't. So like, should I be concerned? Should I be worried? Like, why has it lasted so long when it's supposed to be just like a cold and goes away in a few weeks*?" – Taylor

She began to reconsider her risk and started to be concerned that "*the longer it's in your body, the higher that risk is going to be*." Despite this, her emotions were mixed, demonstrated by her saying "*I wouldn't say I'm massively concerned and it plays on my mind and I'm really worried,*" in contrast to shortly afterwards referring to herself as "*I am worried now.*" She then went on to share that "*the whole cold virus, I think that that really bothers me because it really gives a certain impression that clearly it's just not accurate.*" In light of this uncertainty, and coupled with the impact of no access to a HCP, perhaps this represented how Taylor's emotions felt changeable and perhaps unpredictable as she tried to process the impact of hrHPV

Ruby also reflected low concern prior to testing positive, perhaps anticipating a positive test result, based on knowledge of hrHPV prevalence. She described being "*distracted*" and "*just assumed everything would be fine*." However, whilst she anticipated receiving a positive result and referred to this as *"a secondary issue*," she had not expected her result to be positive for cell changes, perhaps explaining the initial panic described as "*a frenzy*." In addition, she expressed "*big concern*" of “*does that mean that like I've given this to my boyfriend*.” Similarly to Lakshmi, Ruby seemed to assume that it would be her who had contracted hrHPV and then given it to her boyfriend, which maybe suggested that receiving a positive test result comes with some sort of assumed responsibility.

Ruby found it difficult to sit with uncertainty around how long she had had hrHPV, leaving her wondering when she had contracted it, and how long it had taken to develop cell changes. Having no indication of how quickly the cells had progressed seemed difficult for Ruby and this was perhaps supported by her sharing that she likes “*being clued up on these sorts of things. I’m very much a like, want to know everything person.”* Furthermore, Ruby’s concern about time was something she repeated, emphasising the intensity of this fear:

“*That was one thing I really remember saying to my mum and have said since quite a lot as well. I have no way of knowing when this happened, or how quickly it's got to the stage that it is, and I find that quite scary*” - Ruby

Ruby was also afraid of further medical intervention, and shared that she “*really didn’t want surgery*.” This perhaps suggests immediate medical intervention was more distressing for Ruby than the idea of developing cancer in the future. Ruby perhaps found intimate examinations to be overwhelming, as prior to screening to she expressed “*I haven't had loads of like intimate, erm, consult-, like consultations that are like around that area, so erm, I guess that was my main concern,”* with the word “intimate” perhaps suggesting elements of shame or embarrassment. Ruby described a detailed picture of how the Colcoscopy would look with the idea that there would be “*loads of people…looking at my cervix*” suggesting her feeling medicalized or de-humanised by the process.

Grace also “*anticipated having a positive result*” based on the known likelihood of receiving a positive result, and described “*I just got on with, with normal life*,” after testing, perhaps alluding to the benefits of knowledge. However, Grace did also describe some concern about “*whether it would be more than HPV*,” suggesting she was potentially nervous about a diagnosis of cell changes. She also expressed nervousness when opening her letter, as she compared the feeling to opening exam results, describing this as like when “*your eyes like, just straight down to like, what* *grade you got, like you don't look at anything else on the pape*r.” However, she was quite reassured to see “*low-grade dyskaryosis*” and said she did not feel like “*I'm immediately gonna die, and I don't feel like I have cancer*,” despite her initial concern about cell changes. This was again perhaps suggestive of her understanding of medical terminology, meaning she could interpret the results and understand that this equated to low risk. Grace also described feeling “*a bit of anxiety*” about cell removal treatment, based on her experience of having witnessed LLETZ treatments at work. The level of sensory detail in this memory perhaps suggested it’s significance in relation to her fear:

“…*like literally she gripped my hand through the whole procedure, so I've seen, like, first-hand people in excruciating pain from having it…and like, I remember when I watched it as well because it's like, umm, what do they call it, like the loop thing, like it like burns, like you can smell the, the, the cervix like...”* - Grace

On reflection, she felt the overall impact of testing positive for hrHPV had been “*more positive*” than negative, perhaps because of its role in helping to build further “*trust*” and “*open communication*” in her relationship, or perhaps because she was able to use the experience to support others who might hold less knowledge.

“The sense that I felt the diagnosis being more than just about me, like having that sense of, ok I can share this and I can sort of give this back and like actually make something positive about it, made it a lot more manageable” - Grace

Sub-theme 4b: The Impact of hrHPV on Self-Identity

This sub-theme spoke to varying impact of hrHPV on self-identity. For some, testing positive for hrHPV changed their understanding of their health, and for others how they saw they saw themselves in relation to others. Others were able to maintain a more stable sense of self or felt that the impact was minimal or only temporary.

Clara described a realisation that cancer can happen to anyone, supported in her repeating the phrase “*I didn't think it would happen to me,”* during the interview, suggesting a potential shift in sense of self, in relation to cancer. Furthermore, perhaps Clara also started to picture herself as someone who would be diagnosed with cancer, almost as if this became part of her identity.

"…genuinely went into thinking I was dying and having to kind of make arrangements for that. Or you know, thinking ohh how am I gonna, you know, go through cancer journey and things…" – Clara

This was perhaps why Clara identified as having "*a cancer scare, or a near death experience,"* because she was *"convinced I was gonna die."* This maybe suggested that cancer became an inevitable part of her life story, even without a diagnosis. She also compared herself to an "*older dog,*" with "*lumps and bumps*" suggesting this experience encouraged Clara to see herself as older and starting to experience health difficulties. This faded after receiving her Colcoscopy results, but Clara was left with a remaining "*sense of mortality,"* suggesting that whilst this no longer seemed inevitable, it left behind a lingering sense of vulnerability.

"I'm literally just like everybody else. Erm, so this can happen. It can happen to me, and, and my other kind of people around me as well. " – Clara

Clara also expressed temporary regret that she "*should have had kids before, like, why haven't I done it, you know, when I was a little bit younger and still in kind of good health,"* perhaps further emphasising this change, but also the potential loss of identity of her future as a mother.

Penny Lane also expressed difficulties adjusting to seeing herself differently. She experienced intense feelings of grief for the loss of a planned future following a diagnosis of cell changes. She associated this with needing cell removal treatment which she in turn linked with risks to future pregnancies.

"…*when I first heard of the results came with abnormal cells, actually the first thing I frightened is if I have a CIN…two or three, it will called for the clean the surface of the abnormal cells and it causing erm, risk of pregnancy, erm early end of erm pregnancy*"

She shared "*I cried because, I assume I'm not gonna have a child,*" suggesting strong emotional intensity. This was supported by Penny Lane describing her fear and heartbreak to be more intense than fear of developing cancer, which she described as "*it's not sounds like it's supposed to be but who knows*," perhaps suggesting she was not expecting this reaction. The second positive test result was more difficult for her to discuss, and she became tearful, perhaps emphasising its rawness, despite her now knowing "*it's not gonna affect me having a child or not*."

"…I really, in future, planning to have a child so, erm for me thought about if i have a miscarriage, erm, not getting cancer, i afraid from having a miscarriage…" – Penny Lane

Penny Lane found it hard to accept membership into a group of women considered to be at higher risk of developing cervical cancer. Maybe if Penny Lane accepted this, then cancer would have seemed a more permanent part of her identity.

"I will live with that to try and survive and not getting cancer, more erm, belonging and more risk group than other 90% women." – Penny Lane

Penny Lane also shared that the views of those around her had changed, as she described a colleague who "*approach me like I get the diagnosis of cancer,"* which for Penny Lane perhaps reinforced this idea that she now belonged to an at-risk group. This experience led Penny Lane to engage in more online research where she *"learned it could be coming back. It's, the [cell removal] removal is not end of it."* This realisation that sometimes cell removal treatment was not 100% effective, perhaps intensified her belief, as she described that this left her feeling *"as like a survivor now"*

hrHPV prompted changes to several aspects of Ruby's sense of self, firstly in consideration of herself in relation to others. For example, she began to wonder Which relationships to prioritise between Mum and partner. Perhaps the link between hrHPV and sexual and reproductive health prompted this because it could have more implications for the future of her relationship with her boyfriend than with her Mum.

*"…like going up to it, I spoke to my friend, i was like, wait, do I have *partners name* in it or do I have my mum in it…"* - Ruby

Furthermore, testing positive for hrHPV also encouraged Ruby to consider her potential as a child-bearing person. Whilst Ruby always wanted to be Mum, she shared this was "*not something that we're thinking of [yet],*" and despite this, hrHPV led to worry and concern about her future potential to carry a child.

"…i guess that did, back to your question, did change my sense of self as well, because I felt like someone with a partner, with a, I also felt like it brought like the possibility of pregnancy about quite a lot in my mind." – Ruby

Ruby attributed fear of further medical intervention to possible complications for future pregnancy and described this as "quite an emotive part," alluding to the fear that natural conception might no longer be an option, should she require surgery.

"*I really want to be a Mum and I would really want to carry a child if I can, and so i don't wanna put any risks in the way of that."* - Ruby

Ruby also alluded to a transition from her younger to older self, expressing that it "*definitely made me feel old..*." Ruby described that she *"feel[s] like at such a like, crossroads in adult slash teen, like teenage young adult point,*" and emphasised that when younger *"when you're sick, you want your, you want your mum"* but how this perhaps felt different for her. The phrase *"when you're sick"* perhaps also emphasised the impact on Ruby's view of her health, supported by her early admission of "*Oh my God. Like I just think of myself as a healthy person."* This showed that for Ruby hrHPV maybe represented a change from being healthy to unhealthy.

"…*it meant it was like the first thing that I was genuinely like, concerned about to do with my health, that I'd like ever had, really."* – Ruby

Taylor was initially hesitant to suggest that hrHPV had impacted her sense of self, with her first thoughts seeming to be potentially dismissive.

"*No, sorry, that's, I don't have more to say than no, I, I don't think it has… it just kind of hasn't…" – Taylor.*

On reflection, Taylor considered whether the comparison to a cold virus was potentially protective, perhaps because it emphasised the fleeting nature of the virus, and it's prevalence. However, she almost seemed undecided when she shared "*although I kind of dismissed that since it clearly doesn't apply to me,"* suggesting that perhaps this was still a question in her mind.

"…they make it sound like having the virus itself is very common, and it can kind of just come from nowhere and go. So, I think that's probably why it's not had an impact on like how I see myself." – Taylor

Taylor perhaps felt more able to consider the impact on her health, as she reflected that cancer has always been in her thoughts, perhaps because related to "*cancers in my family,*" which maybe makes cancer seem more probable. This seemed to be a familiar narrative in her family, so perhaps associating herself with a higher chance for cancer has always been part of her identity, supported by her sharing "*there's always been something in the back of my mind, like if I take any four women in my life, or any four people, one of us is going to get it, so why wouldn't it be me?"* She also suggested that this idea of herself as someone at higher risk for cancer was perhaps linked to wider narratives, and statistics suggesting that cancer is very common.

Sub-theme 4c: Sense of Powerlessness and Taking Back Control

The sub-theme spoke to feelings of powerlessness, and to taking back control in the form of health-related behaviours and decisions.

For Penny Lane, the lack of available treatment options left her with this sense of powerlessness, as she realised there was nothing she could do after she "*searched for vaccination options, there is none. Screening options for male, there is none*." Her frustration was expressed by Penny Lane suggesting she would pay for additional healthcare when she asked her GP "*is it ok to vaccinate it, even I could pay?"* This perhaps suggested a slight sense of desperation to stop the hrHPV from progressing. This lack of control was seemingly even more distressing after also testing positive for cell changes, perhaps with the perception that her diagnosis was worsening emphasising her lack of control. She was also further frustrated by the management protocol, again being told to wait. Despite her initial fear of the impact to pregnancy, once Penny Lane knew that there are limited side effects, she felt more powerless when faced with the idea of not being able to have the surgery.

"*…thinking about I will get only CIN one and it's just gonna be, erm, the screening after a year, actually this option more frightened for me because I just don't wanna stay, erm, without screening for a year, because there is a high risk of abnormal cell, not even just virus now. So it's more scary..."* – Penny Lane

In light of limited options, Penny Lane tried to take back control by engaging in health-related behaviours. She explained that her and her husband *"examine ourselves more"* even though hrHPV "*is not generally coming with symptoms*," perhaps suggesting this behaviour to be anxiety driven. Drawing on oncology-related knowledge, Penny Lane decided to prepare herself for surgery by means of prehabilitation, actively working to improve her current health, via exercise, nutrition, and mental wellbeing. For Penny Lane, perhaps this helped her to feel reassured and prepared, should she be told this was needed. It also perhaps gave her something to focus on within her control.

"it's definitely give me the, erm, or remind me the best wish is health from the new year." – Penny Lane

Similarly, the lack of treatment options left Lakshmi feeling uncomfortable as she shared "*I might have been more comfortable with it or what, erm If there was like a very clear treatment"* and described *"having to come to terms with the fact that, like, OK, well, there's nothing to be done".* This phrase suggested that this process was difficult, and a sense that she had exhausted all options. This was perhaps supported by Lakshmi repeating a similar phrase to this several times. In response to this powerlessness, Lakshmi turned to online research perhaps to find different information which might give alternative options.

"*I looked at the NHS website, I probably looked at Web MD, although I don't really take much of WebMD seriously, but I think it was like various American health websites, like John Hopkins and things like that, erm probably Wikipedia. I think I read the whole Wikipedia entry page for HPV."* - Lakshmi

The extent of Lakshmi's research perhaps suggested this to be anxiety driven, supporting the possibility that she was trying to relieve this uncertainty. Although perhaps intended to reduce the feeling of powerlessness, Lakshmi gave the sense that it did not provide the sense of control desired. Although, it is possible that it helped her to move towards acceptance, which might have helped it to feel more manageable.

"…I think, it didn't, like it both made me feel like, OK, well, I haven't got a choice, I do have to just wait until next year, that's just what seems to be the erm, standard practice across the board is you just wait… - Lakshmi

Clara also turned to the internet, perhaps too to regain a sense of control, and described "*hoping that there'd be different information when I went on there again."* This perhaps emphasised the impact of uncertainty created by hrHPV, coupled with a sense of powerlessness. Although, this was done with the intention to increase control, it seemed to have the opposite impact, perhaps instead signalling that cervical cancer was inevitable, leaving Clara feeling "*quite scared,"* and potentially no less powerless.

"*I was just trying to read as much about it and read kind of good stories about it, and yeah, people saying, oh, you know, it's nothing to worry about, which I'm sure there were, but I don't remember seeing that. I just remember seeing like, cervical cancer…" – Clara*

For Ruby, there was a sense of powerlessness throughout, and she alluded to lack of choice often. Even when considering screening, although she believed "*if you get the opportunity to test for something like you should do it*," she also suggested a link to "*that's what I want my career to go down, so I feel like I should set an example for that*," suggesting strong ties to her professional identity driving her decisions.

"…I almost feel like I have less choice in that anyway, because that's kind of something that I've almost promised to myself…" – Ruby

For Ruby, she felt as though there was distinction between before and after someone decided to become pregnant, when considering choice associated with intimate examinations. She therefore felt unprepared for multiple examinations, as she shared "*that's a decision that I will make at the time and then in that time, I'll be ready for people to be like all about, like my intimate areas."* This perhaps contributed to her sense of powerlessness in the face of further testing. Ruby also alluded to the idea that when we need to do something to look after our health, this perhaps no longer constitutes true choice. Even though she could say no, she knew she needed to say yes, possibly further emphasising powerlessness.

"…I don't know what I'd have done if it was CIN three. Like, well I think I would have just ended up just doing the surgery, I think that's what would be told, I would be told I'd have to do really, but I don't know how I would feel about that…" – Ruby

Ruby tried to take back control by opting not to receive surgery. She conceptualised this decision as a way to track the progression of the changes, however perhaps this provided bodily autonomy. It seems for Ruby, holding more knowledge and understanding, gave her a greater sense of control.

"…one of the main reasons for [not having LLETZ] that was then I'll have a benchmark of like six months ago this is what it looked like, this is what the diagnosis was. In six months time, what is it going to be like…" – Ruby

Ruby also decided to make some lifestyle changes, choosing to focus on aspects of her health she could control, as she shared "*the easiest thing I think I can do in my person to like destress my body is probably less alcohol and less caffeine."* This suggested that Ruby perhaps found it helpful to feel like she was supporting her health, rather than just waiting. This is supported by Ruby later suggesting *"i think in general, having been less stressed and stuff has, has definitely helped,"* despite not attending any further tests confirming this.

However, elements of these health-related behaviours were perhaps also unhelpful. For example, Ruby shared that she "*bought supplements, like I went for the whole shebang and then I, I had to like really save this month"* maybe representing an element of desperation to regain a sense of control. Her health-related behaviours also seemed to bring up some past difficulties, leaving her feeling that she "*need[ed] to be perfect*." Ruby shared that she had spent a lot of time when younger "*on the toxic health side of the Internet,*" perhaps suggesting a pre-existing sensitivity to health-related anxiety. Although she perhaps initially felt more in control by engaging in these behaviours, there was also an increase in associated anxiety.

"…then when I did go out with my friends and did have a drink, I was really upset about it, like the day after, and I think I was putting quite a lot of pressure on

myself to put my body into this perfect state of non-stress that would like not progress that HPV." - Ruby

Being told to wait and see was difficult for several women, including Taylor. She expressed an increasing sense of powerlessness in the face of multiple positive test results receiving the same care plan of *"wait again until next year"* and expressed that this *"doesn't sit comfortably"* for her. This is perhaps supported by Taylor's repetition of *"nothing will be done,"* during the interview suggesting a sense of feeling forced into accepting this sense of uncertainty and lack of control.

In contrast to some of the other women interviewed, Taylor decided to take control by seeking reassurance from a HCP during a routine contraception review appointment. Taylor perhaps saw this as an opportunity to seek some answers, maybe hoping that this would help her to feel like she had more control over the situation and had a better understanding of what to expect.

"I took the opportunity there thinking, ok, she's a nurse…surely she'll know something or will be able to give me some advice… And she just had nothing." – Taylor

Chapter 4: Discussion

This chapter discusses an overall summary of the results, then situates this in the context of wider research findings and psychological theory. Then the chapter discusses the strengths and limitations, clinical implications and suggestions for future research.

Main Summary of Findings

The aim of this study was to explore the emotional experience of women testing positive for hrHPV. Specifically, this study aimed to answer the following question: How do cis-gender women in the UK make sense of the experience of testing positive for hrHPV?

Six women who had tested positive for hrHPV were interviewed and data was analysed using IPA. Four GETs were formed. These themes were: The narratives held about hrHPV, The experiences of the delivery of services and wider NHS relationships, The relational experience of hrHPV, and Cis-women's accounts of testing positive for hrHPV.

These themes explored a range of responses to testing positive for hrHPV throughout the various stages of pre-diagnosis or testing, at the point of diagnosis or testing, and over time as individuals began to reflect on these processes or even receive additional test results. Women expressed a variety of emotional responses including fear and anxiety about the future, shame, shock, disbelief and for some even relief, grief for potential and actual losses (for example to their perceived health or future ideas of motherhood), and impacts on their identities and ways of relating to others and the systems around them. The results also emphasised the impact of time and how responses could change depending on where someone was in the process, and in turn how each individual experience could be perceived differently despite following objectively similar pathways.

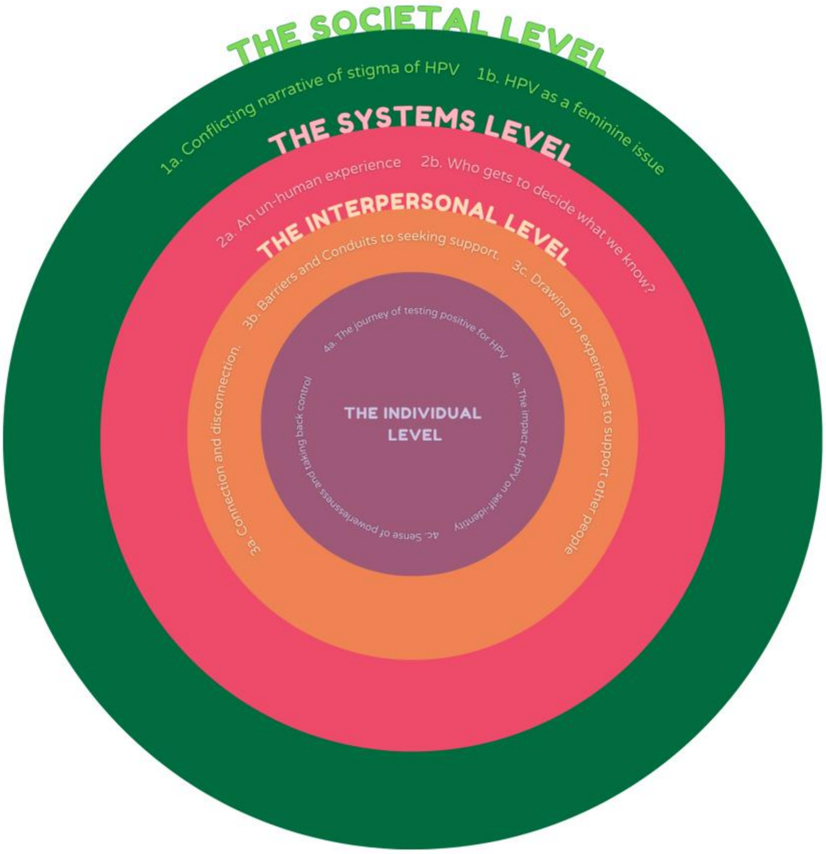
Conceptualisation of results

Bronfenbrenner's Ecological Systems Theory (1977)

To support the conceptualisation of these results, parallels were drawn between the research themes and Bronfenbrenner's Ecological Systems Theory (1977). Bronfenbrenner's (1977) model suggests that the experiences of an individual cannot be properly understood without due consideration of wider levels of context. This suggests that individuals are influenced by what happens around them, both in terms of their direct relationships with others, systems and broader aspects of social and political context but also how these layers interact with one another. Bronfenbrenner's (1977) model also acknowledges the impact of time and how this specific layer of context will inevitably influence what happens at every other layer of an individual's environment. An Ecological perspective of health has long been argued as necessary (Green et al., 1966) particularly given the lack of success attributed to individually aimed health interventions from a public health perspective (Trickett & Rowe, 2012). Supported by other research, in health contexts this emphasises the importance of considering the impact at and between each layer of context on an individual's experience of their health (Lehman et al., 2017).

Similarly to the original model, the overarching themes can be understood as interacting with one another across the different layers of context, representing how people as individuals also exist in relation to others and interact with these wider systems. An overview of this conceptualisation can be seen in Figure 3. In line with Bronfenbrenner's (1977) model, At the societal level themes can be understood to sit within the Macrosystem, a representation of the wider ideologies and attitudes held within the culture of study. The systems level themes can be understood as the individual's interaction between themselves and the Exosystem which represents the impact of how individuals must exist in the presence of systems which often operate in ways which are outside of their control or influence. The interpersonal level themes can be viewed as how women interact with those in their Microsystem, such as friends, families and partners. The Mesosystem and Chronosystem are present throughout, representing how all parts of the model interact with one another and are subject to this specific time. For example, all the women in this sample fell within the same age group, if this research were to be repeated with women of an older age group or with the same women in twenty years the factors discussed at each level of the diagram might look quite different. Finally, the individual level themes can be seen to sit at the centre of the model and represent the impact of the individual's interaction with all the broader layers of context. When considering the impact of testing positive for or being diagnosed with hrHPV for the women in the present study, it is important to acknowledge the impact from an ecological perspective which suggests that these layers of context must offer conditions conducive to promoting good overall health and wellbeing, including mental health (Green et al., 1966). Furthermore, the Bronfenbrenner (1977) model supports the emphasised importance of consideration for each layer of context and how this impacts experience which was highlighted by all the women interviewed in this research. Each Layer of context will now be discussed alongside additional research and theory where relevant.

Figure 3: An overview of the subthemes and how they sit across different levels of context



At Societal Level: The Narratives Held About hrHPV

The themes within this level of context highlighted how narratives can impact women's response to testing positive for hrHPV, and all women interviewed spoke to the varying impact, particularly in the context of stigma and the feminisation of hrHPV within the wider social and political context.

This was in line with the findings from the systematic review (Fisher et al., 2024; Hilton & Smith, 2011; Martin et al., 2011; Mupandawana & Cross, 2016; Nadaryznski et al., 2017). All women spoke about stigma, however due to the elusive nature of hrHPV, being "lesser spoken about," this also left women feeling unsure of how stigmatised hrHPV might be, in comparison to other STIs. This was perhaps supported by previous research suggesting that the stigma is less than that associated with lrHPV or genital warts (Martin et al., 2011; Nadaryznski et al., 2017). Despite this, many women expressed concern over how others might respond, for example Taylor expressed concern of telling others, particularly those with less understanding of hrHPV (Perrin et al., 2006; Peterson et al., 2021), perhaps linked to stigma associated with fear of social isolation (Fife & Wright 2000). This finding is particularly poignant when considering that up to 80% of people will contract a form of HPV throughout their lifetime (Scott-Wittenborn & Fakhry, 2022). However, this was in line with research suggesting that knowledge of others might impact how hrHPV is perceived (Kahn et al., 2007).

There was also potentially a relationship between women's own knowledge and stigma. Taylor expressed that she was not certain on sexual transmission and alluded to this perhaps being protective as to why she did not feel as stigmatised (Kim, 2012). This sense of uncertainty around transmission is unsurprising, given recent questions posed by researchers over modes of transmission (Petca et al., 2020). Grace suggested that her high level of professional knowledge helped her to be aware of the stigma, but not to feel impacted by it. Clara on the other hand reflected that she had come away from the experience feeling "a bit unclean" even after learning how common it is. These findings were somewhat in line with Waller et al, (2007) who suggested that having knowledge of sexual transmission can negatively impact stigma and shame, but that knowledge of prevalence can lessen this impact.

Women also talked about sexual transmission, perhaps suggesting transmission to be a catalyst for stigma (Perrin et al., 2006). It is possible that women interviewed were not aware of alternative modes of transmission (NHS, 2020; Petca et al., 2020) and only heard narratives that linked hrHPV with factors such as higher number of sexual partners or younger age at first sexual contact (Baseman & Koutsky, 2005; Ferris et al., 2020; Pourmohsen et al., 2018) which could have contributed to feeling stigmatised. For some women, they found it difficult to navigate feelings of stigma and shame, alongside what Lakshmi considered to be "feminist" viewpoints and values, and perhaps expressed surprise at feeling stigmatised despite this positioning. It is possible that some of the external narratives have been partially internalised, perhaps leading to this unexpected additional burden of stigma (East, 2009). This perhaps falls under Goffman's (1963) definition of stigma which considers "blemishes of character" whereby women have internalised narratives suggesting those with STIs are to be considered "promiscuous."

Ruby reflected on her past sexual encounters, perhaps suggesting a change in appraisal in line with findings which suggest feelings of stigma are impacted by beliefs that hrHPV is a result of "incautious" behaviour (Peterson et al., 2021). This perhaps suggested blame, which could be both external or internal, as was demonstrated by Lakshmi who expressed guilt for having hrHPV and felt blamed in the context of disclosure. Research into vaccination attitudes also suggested beliefs that women held blame when testing positive for hrHPV (Mupandawana & Cross, 2016). Furthermore**,** when women were positioned as to blame for developing cervical cancer, the level of moral disgust and discrimination shown was higher than when there was no known cause suggested (Shepherd & Gerend, 2014). In addition, an SLR of stigma in cancer patients suggested most of the research has focussed on stigma in lung and cervical cancer, whereby there is a known cause linked to socially unfavourable behaviour, rather than skin cancer, which is linked to a less socially undesirable behaviour (Lebel & Devins, 2008).

Several women interviewed also expressed frustration at the responsibility and burden of hrHPV being placed on women, despite the potential impact for men and their role in transmission. As noted in the introduction, hrHPV has typically been framed as a women's health issue (Daley et al., 2017; Thompson, 2010) and only more recently an issue for men who have sex with men (NHS, 2023a). Clara emphasised division of labour differences, created by female only testing, as it leads them to grapple with disclosure. In comparison, as no testing is available for men, they have no way of knowing if they have hrHPV, and therefore perhaps feel under no obligation to consider disclosure. This disparity in testing allows for dismissal of active male sexual responsibility (Martin et al., 2011; Thompson, 2010). In turn, this reduced responsibility for men then only increases responsibility and blame for hrHPV held by women (Daley et al., 2017). Consequently, as highlighted by Penny Lane, this construction of hrHPV also means men are unable or may be less likely to access relevant healthcare services (Daley et al., 2017). This is supported by Nadarzynski et al, (2017) where it was suggested that feminine connotations might deter some men who have sex with men from vaccination.

Women also felt led to believe that hrHPV only impacts people who are born with a cervix. Whilst this research focussed only on the experiences of women, it has also been suggested that this lack of understanding was also applicable to men (Fisher et al., 2024; Martin et al., 2011; Nadarzynski et al., 2017). Thompson (2010) argued these misunderstandings were because women's bodies continue to be thought of as "the source and focus of problems and disease," suggesting that these feminine frames and narratives of sickness in women leave less space to consider how the bodies of men may also need to be "regulated." Although gender-neutral vaccination is now encouraged in the UK, and similar incidence rates can be seen in cervical cancer and hrHPV related oral cavity cancer in males (Information Centre on HPV and Cancer, 2023), recent statistics suggested a consistently higher rate of vaccination in girls than boys (UK Health Security Agency, 2024), supporting calls for an ongoing need for education regarding hrHPV in men and boys (Sherman & Nailer, 2018). In addition, there remains no routine screening options for hrHPV in men, with this disproportionately weighted responsibility thought to be rooted in societies need to control or limit what women can and cannot do with their bodies (Thompson, 2010).

At the Systems Level: The Experiences of the Delivery of Services and Wider NHS Relationships

The themes at systems level spoke to women's experiences with the NHS system. All women interviewed spoke to either the impact of a lack of human contact, or of what information was or was not given by services during the process. An importance facet to this level of themes to consider could be how systems can impose restrictions or processes on individuals outside of their control (Trickett & Rowe, 2012) which can inevitably impact how their experience.

Several women discussed how receiving the results via letter or text negatively impacted their wellbeing, with it being described as “uncaring,” and giving the impression that you “just get on with it.” Women generally felt that they would have benefitted from an invitation to ask questions, with Lakshmi and Taylor expressing reluctance to take up additional HCP time. This experience is conflicted with the healthcare systems role in supporting the “prepared public” to feel supported as active decision makers in their care (NHS Improvement, 2019). However, perhaps this lack of additional input is driven by epidemiological data to suggest that most women who contract hrHPV will clear the virus within a short period of time or may not even realise they have contracted it at all (Scott-Wittenborn & Fakhry, 2022). It is also important to consider differences in dynamics between the patient (also considered a consumer) and the product (also considered the NHS), as described by Berry et al (2017) in the context of healthcare as a necessity, and how this potentially placed patients in a position of lesser power. It was suggested that this dynamic can help to explain why patients may accept a lesser standard of care by a healthcare service.

Although for most women, hrHPV can have relatively short-term health impact, the emotional impact can be more lasting. When considering HIV testing guidance, it is accepted that a positive result should include a follow-up consultation, with some suggesting this to be good clinical practice for any form of “bad news,” to help monitor patient wellbeing (D’Angelo et al., 2021; NHS Tayside n.d.). In STI research, there was a preference for results over the phone, than via text (Ling et al., 2010) with 68% of patients expressing discomfort with receiving a non-HIV STI test result via text, and 38% via letter (LaRocque et al., 2015). Furthermore, there was generally an expectation from women that a positive hrHPV would involve a call or follow-up appointment (Symmons et al., 2021). This evidence supported that a conversation was warranted when testing positive for an STI, which then begs the question as to why hrHPV is managed differently.

Women were also left feeling “fooled” by the lack of information, or the kind of information given by the NHS. For example, Ruby was frustrated by her original letter only describing her result as “abnormal,” and Grace expressed disappointment at the potential outcomes not being explained during screening. Many women still did not feel able to make sense of the diagnosis, consistent with previous research (Marlow et al., 2020). The research suggested that questions are common among women who test positive for hrHPV and that they feel the responsibility to provide information lay with the NHS, not the patient to seek out more (Symmons et al., 2021). Previous research also highlighted the importance of more individualised information, particularly in the context of multiple positive test results (Symmons et al., 2021).

It therefore seems there has been little consideration for patient preferences in the current screening protocol. Since the COVID-19 pandemic, this has been reflected in several areas of NHS care. An example being less patient choice between virtual vs in-person appointments under the guise of the post pandemic “new normal” (Redhead et al., 2023). There also seemed to be a lack of clinical transparency (Llewelyn, 2013) despite the recognised importance of patient and public involvement in service development (Department of Health (DOH), 2021) and the role of transparency in the “No decision about me, without me” policy (DOH, 2012). The DOH (2021) suggested that patients must be given adequate information about their care to be able to take a greater role in decision making. It also acknowledged that power cannot be held by patients, if all the decisions are made by parts of the system too far removed from their experiences. Fenney (2024) also made an important distinction between enabling patient autonomy and withdrawing support, suggesting that managing a result alone is not conducive to empowerment and that it is important to feel supported to understand and manage the diagnosis in community with others.

At the Interpersonal Level: The Relational Experience of hrHPV

The themes at the interpersonal level described sharing the experience of hrHPV with others, feeling connected or disconnected from others, the barriers and conduits to seeking support from others, and being able to use the experience to support others. In line with previous research, several women were anxious the impact of hrHPV on their relationships (Bennett et al, 2019; Bennett et al., 2021). In the present study, women were sharing their results in the context of heterosexual relationships, perhaps increasing this sense of anxiety, due to assumptions that men are more likely to make judgements. However, for many women hrHPV contributed to stronger, deeper interpersonal relationships. For example, Ruby and Grace both described deepened connections with their Mum and partners following sharing their results. This was consistent with previous research suggesting relational growth, particularly in the context of shared experiences (Kosenko et al., 2015). This was also consistent with a systematic review reporting that some women experienced not only acceptance and concern from a partner, but also a deepened sense of connection (Bennett et al., 2019).

Some other women's experiences were more negative, or they anticipated it to be negative. For example, Taylor expressed not wanting to share the result with anyone who was not female, and Penny Lane described her friend's relationship as struggling with where hrHPV had come from. This uncertainty was echoed by Kosenko, Hurley and Harvey (2012), where women found being unable to pinpoint the timeline of hrHPV to have a negative impact on some of their sexual relationships. Some women also found the process distressing when the experiences of others triggered their own worries. This was consistent with previous research suggesting this to be a source of uncertainty and anxiety for women when testing positive for hrHPV (Kosenko, Craig and Harvey-Knowles, 2012). Lakshmi also shared a sense of guilt (Newton & McCabe, 2005) for hrHPV, and that it had become a point of conflict for her relationship (Bennett et al., 2019).

Women discussed several barriers and facilitators to sharing their test results. A common barrier in the literature was the fear of judgement from others, perhaps linked to societal narratives and the impact of stigma (Bennett et al., 2021). There was also research suggesting fear of judgement from peers, and perhaps family (Bennett et al., 2021), which as described by Lakshmi, stopped her from seeking support (Kosenko, Craig and Harvey-Knowles, 2012). Penny Lane and Lakshmi also described not wanting to worry others, which was consistent with sexual partners (Bennett et al., 2021; Waller et al., 2007), however, were referring to family members. This communication barrier has also been reported to be distressing for people diagnosed with cancer as a barrier to communicating their own emotional difficulties (Ussher et al., 2006). A novel finding was the idea of hrHPV not being serious enough to seek professional support. This was in conflict with research suggesting lower support needs post-diagnosis of cancer compared to pre-diagnosis (Liao et al., 2007), but also the impact of pre-diagnostic supportive care in reducing anxiety (Liao et al., 2010). This difficulty was perhaps further complicated by the recent closure of Jo's Cervical Cancer Trust, the only UK charity providing support throughout the process from screening to treatment. Perhaps women were drawn to more conversations, due to the lack of availability of discussion within the NHS or third sector organisations.

Facilitating factors were described as validation and solidarity, feeling safe enough in the relationship and feeling encouraged by openness modelled by others. Both Lakshmi and Clara touched on the idea of feeling validated when others shared their experiences and gave reassurances (Kosenko, Craig and Harvey-Knowles 2012). When considering social identity theory, it was possible that women stopped seeing themselves as a potentially stigmatised "other" and started to see themselves as belonging to a group with shared experiences (Haslam et al., 2009). Ruby also shared the helpfulness of feeling safe enough perhaps because the relationship was well established, this was supported by research suggesting that safeness might vary depending on length of relationship (Netwon & McCabe, 2005). Grace reflected on the impact of growing up with a Mum who was "quite open," an idea well supported in the literature with research suggesting this encourages more open conversations about sex (Kesterton & Coleman, 2010; Rosenthal & Feldman,1999), as opposed to parents who limit these conversations which can reinforce that talking about sex is inappropriate (Stone & Ingham, 2002). Clara, Grace and Taylor all alluded to the idea of using their experiences to support others, and Kosenko et al (2015) described this phenomenon as "serving as a witness," also noted to be present in other STI research, for example in Gay men diagnosed with HIV (Schwartzberg, 1994). We could also consider the lifespan model of developmental challenge (Hendry & Kloep, 2002) which suggests that different individuals have access to different resources (e.g. social, psychological, financial etc.) which can impact reactions to challenges. This is also impacted by the interaction between these resources and the nature of the challenge. For Clara, Grace and Taylor, perhaps they felt able over time to meet this challenge "successfully," allowing space for developmental growth, which in turn gives them the resources to provide support to others (Hendry & Kloep, 2002).

At the Individual Level: Cis-Women's Accounts of Testing Positive for hrHPV.

The themes aligned with sitting at the centre of Bronfenbrenner's (1977) model described the impact of testing positive for hrHPV at the individual level with the acknowledgement of how these responses are impacted by the factors at every other layer of context. Women talked about their emotional journey of testing positive, with this varying and changing over time. They also talked about the impact of powerlessness and control and on sense of self. All women spoke to the different emotional experiences described as surprise or anticipation, fear, optimism or relief, and sadness. These findings were in line with anticipated emotions highlighted by the SLR (Cadman et al., 2014; McCaffery et al., 2003; Nadarzynski et al., 2017;).

Whilst previous research has used a cognitive behavioural framework, this thesis references a compassion focussed therapy (CFT) framework considering the threat, drive and soothe systems, for its usefulness in considering impact of emotionally distressing experiences for an individual (Gilbert, 2009). Underpinned by the Social Mentality theory (Gilbert, 2000), CFT also lends itself to a framework which allows us to understand these emotional processes relationally, which when considering shame and stigma sits well alongside understandings of health-related shame and stigma theory (Dolezal, 2022). Furthermore, when considering this from a clinical perspective, CFT was initially developed to be a transdiagnostic approach with an emphasis on managing shame across several different diagnoses which in theory could perhaps be considered helpful for supporting women experiencing shame in the context of different difficulties when testing positive for hrHPV (Craig et al., 2020). Women's experiences will often fit into more than one system, which represents the dynamic and changeable state of emotion regulation between the systems as they work to find a suitable balance.

The Threat System. Some experiences could be understood in the context of an over-active threat system within CFT (Gilbert, 2009), associated with feelings of anxiety, or being "on guard". For example, several women expressed emotions of shock and surprise, often attributed to testing positive at first screening, having a previously normal screening, being in a long-term relationship, or beliefs about safe sexual behaviour (Bennett et al., 2023; Daley et al., 2010; McBride, Tatar et al., 2021). Although research suggests that it can take years for hrHPV to cause cell changes (Baseman & Koutsky, 2005), these responses suggest that perhaps some women may feel worried that they have had hrHPV for many years already, especially in the context of a first cervical screening. The most common emotional response was fear (Perrin et al., 2006). For some, this was linked to cancer (Kahn et al., 2007; Kosenko, Hurley and Harvey, 2012) and was particularly important for women with identified cell changes, consistent with previous research suggesting sexual transmission to be less distressing than the knowledge of cell changes (O'Connor et al., 2014).

Another common fear was of further investigation, with some women alluding to the unknown factors of Colposcopy (Bosgraaf et al., 2013), with previous research suggesting pelvic exams to be one of the most common feared medical interventions (O'Laughlin et al., 2021). Furthermore, one woman alluded to a fear not being given pain relief, typically offered less to women of colour (Hoffman et al., 2016), based on beliefs of higher pain thresholds (Bendelow & Williams, 2002). Some women feared for the impact of hrHPV for their partner, a concern also raised by women in previous research (Bennett et al., 2019; Bennett et al., 2023).

Women also spoke about the impact of hrHPV on identity. Within CFT, it was possible that hrHPV caused threat to sense of self. This was a novel finding as identity in hrHPV has often only previously been discussed in the context of stigma and hrHPV as an STI (Barnack-Tavlaris et al., 2016). This profound impact on identity can also be seen in HIV research, with some participants feeling forever changed post-diagnosis (Flowers et al., 2011).

Testing positive for hrHPV also represented a change from self as healthy, young and strong to older and more vulnerable with the potential to develop cancer, a finding somewhat echoed by Kundrat and Nussbaum (2003), who suggested that participants with an “invisible illnesses” are more likely to perceive themselves and be perceived by others as older, and also report a greater awareness of their mortality (Kundrat & Nussbaum, 2003). More present in the literature was the experience of loss of motherhood identity (Perrin et al., 2006). In the current study, this was often feared by women with cell changes in the context of surgery (Kosenko, Hurley & Harvey, 2012).

The Drive System. Some women also appeared to speak from the context of activated drive systems, perhaps following an activated threat system. For example, powerlessness can be associated with high threat and low drive, perhaps leading to an activation of the drive system to take back control. For example, Ruby expressed a sense of powerlessness in the face of lack of meaningful choice in medical interventions, also reflected in choices between breast cancer treatment or no treatment (Charles et al., 1998). This perhaps showed that when the choice feels meaningless, although it was disguised as a choice, this contributed to a sense of powerlessness and coercion. In light of this, several women, talked about trying to regain control. These ranged from health-related behaviours such as healthy eating, to searching for information online. These types of behaviours have been seen previously, for example reduced sexual risk taking (Kosenko et al., 2015), and more health-focussed behaviours like healthy eating, drinking less, quitting smoking and purchasing health supplements following a positive hrHPV result (McBride, Marlow, et al., 2021). It was also common to turn to the internet (McBride, Marlow, et al., 2021), with nearly all women in one study sharing they sought additional information (McBride, Marlow, et al., 2021), but the information felt unhelpful, conflicting and confusing. Whilst these behaviours and emotions can be helpful, without a healthy balance this could lead to added emotional distress and self-criticism, perhaps reflected in Ruby's struggle to be "perfect."

The Soothing System. When the soothing system is activated, this helps to mitigate the impact of an overactive drive or threat system. In the context of testing positive for hrHPV, this could help women to regain a sense of control and contentment. For example, Grace initially expressed anxiety whilst waiting for her results and further intervention, however, she was also able to draw on her knowledge to reassure herself. Grace perhaps felt more in control as she was able to activate her soothe system. It was possible that this sense of powerlessness and control was mediated by locus of control (LOC) (Rotter, 1966), with research suggesting those with an internal LOC were more likely to engage in health behaviours (Dogonchi et al., 2022). Another study suggested women with higher anxiety levels were thought to exhibit a lower internal LOC (McBride, Marlow, et al., 2021). Finally, Kahn et al, (2007) suggested that women who felt more in control of their hrHPV prognosis were more likely to experience hrHPV as less serious than women who perceived their hrHPV prognosis to be out of their control (Kahn et al., 2007).

Quality Assessment

A strength of this research is its contribution to the evidence base. For example, drawing on Yardley's (2000) criteria, the present research made a valuable contribution as I demonstrated sensitivity to the women's context by drawing on systemic theory (Bronfenbrenner, 1977; Smith et al., 2022), commitment and rigour through the adherence to IPA principles (Smith et al., 2022) and transparency and coherence through my careful description of the research process, use of reflexivity and bracketing.

It was also one of the first exploring women's experiences in the UK after the roll-out of hrHPV primary testing in 2019. Whilst there was previous research assessing the impact of hrHPV (Marlow et al., 2020; McBride et al.,2020; Symmons et al., 2021;) this study provided an up-to-date insight into how hrHPV is received in the current context of screening. It was also the first study to explore this using a phenomenological perspective, and the idiographic nature of IPA (Smith et al., 2022). Furthermore, it provided unique insights into how hrHPV might impact aspects of women's identity outside of changes associated with stigma (Barnack-Tavlaris et al., 2016; O'Donnell et al., 2024).

Strengths and Limitations

An initial strength of this project was the steps followed during the SLR to reduce bias within the selected literature (Adams et al., 2016) by searching outside of peer review journals alone. This aimed to provide a more balanced view of the literature, should relevant research exist (Paez, 2017). However, despite these efforts, it is important to also acknowledge that no such research was determined to meet the inclusion criteria. Furthermore, steps were taken in the SLR not to exclude studies which provided crucial information regarding under researched sub-groups within the UK population (Bibbins-Domingo & Helman, 2022) which were deemed good enough quality when considering the importance of potential research impact for these groups.

By using a qualitative interview design this allowed participants to expand on aspects of their experience which felt most relevant. This was enhanced by my choice of flexible semi-structure interview style (Bryman, 2016). Whilst I used a selection of prompt questions, my use of open-ended questions allowed participants to bring topics that felt important and relevant to their experiences of testing positive for or being diagnosed with hrHPV. Furthermore, by both audio and video recording my interviews, I was able to pick up on some non-verbal cues and facial expressions when engaging in the analysis (Robson, 2011). However, on reflection, a more flexible interview style at times led to some discussions less focussed on the overall research question. In addition, often throughout the interviews I was positioned by participants as someone who could be considered an expert in the topic, and it is possible that participants assumed I held a certain level of knowledge and understanding of their experience which could perhaps have hindered the depth of information gathered (Alsaawi, 2014).

The involvement of EbEs and formal academic consultation in the design stage and throughout the research helped to guide this based on an understanding from both a lived and learned experience perspective. It helped to establish a reciprocal relationship between myself and my participants, and ensured the research was conducted ethically and sensitively to the women involved (Thompson et al., 2009).

The chosen recruitment methodology, whilst time-consuming, allowed for women's experiences to be somewhat separated from specific service-related factors. It also encouraged participation from women from different geographical locations allowing for more accurate representation of this experience across the UK, rather than in a specific location or NHS Trust. Most of the women recruited into the study also held some unexpected similarities including their age group, sexuality and associated profession which could be considered both a strength and limitation of this research. From an IPA perspective, the sample of participants should be more similar than they are different (Smith et al., 2022), as a result these unintended similarities could have strengthened the homogeneity of the sample.

These factors could also be considered from a limitation perspective, for example, all women who participated fell into the age category of 25-34. There was perhaps something about the newness of cervical screening, that amplified the impact of testing positive for hrHPV. Furthermore, as most women identified as heterosexual or had only experienced sharing hrHPV with a male partner, there was a relative level of heteronormativity within the sample which does not provide much insight for cis-gender women in a relationship with another woman. Finally, all women worked in a healthcare setting, although were not providing direct care to other women with hrHPV. Depending on the corresponding area of and level of knowledge and expertise held by the women interviewed, it is possible that this group could be more likely to hold relevant clinical knowledge which may have the potential to enhance their abilities to self-soothe. It is also possible that as clinicians these women had a higher level of trust in clinical research which encouraged their participation (Scanlon et al., 2021) or they were perhaps more likely to engage from an altruistic perspective (National Institute for Health Research (NIHR), n.d.) linked to their professional identities.

Unfortunately, the study did experience recruitment difficulties, despite successful EbE recruitment using the same methods. When speaking with potential participants, many women were unaware of the distinction between hrHPV and lrHPV, therefore some women were potentially unsure on eligibility. Finally, although one woman interviewed expressed subjectively less distress, it was possible that the description of researching emotional responses would have deterred women who found the process less distressing. This was perhaps supported by personal benefit, either therapeutic or for experimental treatments, typically cited as reason for taking part in research (NIHR, n.d.), especially in the context of hrHPV, where there is a lack interaction with HCPs and possible interventions post-diagnosis.

A further strength of this research was during the analysis stages where an additional researcher reviewed the main themes and sub-themes during development for sense checking. This helped me to reflect on my understandings of participant experiences and offered alternative perspectives outside of my own. Due to time constraints, and the amount of time passed between interview and transcription for some participants I was not able to member check with my participants (Harper & Thompson, 2011). However, as this is not always appropriate in IPA analysis, we carried out peer review of my themes as stated above.

Implications of Findings

Based on the emotional impact associated with testing positive for hrHPV, there were strong implications for clinical practice within the NHS to significantly reduce the potential emotional and psychological burden, and in turn reduce the need for specific psychological support services. This is also supported by consideration of the results from an ecological perspective (Bronfenbrenner, 1977), which would suggest that conditions at each level of context need to be suitable for supporting both mental and physical wellbeing of the women interviewed. Firstly, considering the substantial evidence linked to stigma, this suggested consideration for how hrHPV is discussed within healthcare systems and more broadly. Although not present with women interviewed, the SLR highlighted the link between HPV and genital warts, suggesting that this could be a concern for some women. The language used should therefore be carefully considered, not only in NHS communication, but also in terms of vaccination narratives in schools and from educational and political perspectives. Previous research suggested that providing non-stigmatising or stereotypical stories led participants to perceive hrHPV to be less stigmatising (Kwan et al., 2011). In turn, it is reasonable to consider that if women felt less constrained by stigmatising narratives, this would lessen the associated psychological burden.

The findings from this study perhaps also emphasise the potential harm arising from AFAB only testing. Despite now gender-neutral vaccination, both the SLR and interviews highlighted false narratives about hrHPV. With the original link between hrHPV and cervical cancer stemming from the way in which female bodies are positioned (Daley et al., 2017; Thompson, 2010), this societal need to place the "focus of problems and disease" (Thompson, 2010) on women can be seen in many aspects of sexual and reproductive health. For example, the list of medical contraceptives available for women, with limited time and resource dedicated to similar interventions for men (Davis, 2017). By focussing resources on hrHPV in women only, this not only heightens the emotional and psychological burden for women, but also denies men the access to healthcare and the opportunity to take more active roles in sexual and reproductive responsibility. Furthermore, it emphasises the current narratives, reinforcing societal expectations that women will hold more responsibility in heterosexual relationships. This timeline of testing and vaccination perhaps also represents how each layer of context (e.g. the individual, the relational, the systemic and socio-political) can hold influence, and how the presence of a factor at one level can impact the experience at another (Bronfenbrenner 1977). For example, if we consider the attitudes held at the broadest level of context, we can see how this has perhaps then impacted current and previous testing protocols, which in turn directly impacts the experience for women in the UK. This implication is particularly poignant in the context of the current political climate, whereby new governmental commitments have been made to invest in new and improved cancer screening services (Labour Party Manifesto, 2024).

There was also cause to consider the delivery of positive results, with the current format linked to panic and leaving women feeling uncared for (Tiro et al., 2019). These findings were supported by research, particularly in the context of complicated medical histories (Marlow et al., 2020) and pre-existing mental health difficulties (O'Donnell et al., 2024). This perhaps suggested the importance of offering an opportunity to answer questions, particularly in relation to individual health needs. The results suggested that not every woman will need to speak to a HCP and this was supported by previous findings (McBride, Marlow, et al., 2021), however, research also suggested that once women were able to have this conversation, they felt reassured (Tiro et al., 2019), perhaps suggesting that adequately trained, knowledgeable staff should be available for follow-up discussions. Alternatively, this provided support for the role of third sector organisations such as Jo's Cervical Cancer Trust, who until recently offered support for everything related to hrHPV and cervical cancer.

Finally, there could be an argument for consideration of suitable intervention for women impacted by testing positive for or being diagnosed with hrHPV, as noted by Clara, they felt unable to access services associated with cancer, despite experiencing psychological distress. This was perhaps supported by research suggesting women with pre-existing mental health difficulties drew on strategies acquired through therapy to manage hrHPV associated distress (O'Donnell et al., 2024). As highlighted above, there is potential to consider this from both an individual perspective with the exploration around the usefulness of psychological therapies such as CFT, based on its successfulness as a transdiagnostic therapy associated with feelings of shame (Craig et al., 2020). CFT based interventions could perhaps focus on improving compassionate flow either to oneself, to others or from others, introducing a relational aspect to the intervention (Gilbert, 2014). There is also cause to consider a more systemic approach of better integration between physical and psychological services. Whilst not every woman is likely to need psychological support, the present study emphasised this consideration on a case-by-case basis. By positioning this psychological support within screening services, this would allow for a multi-disciplinary approach to consider needs more holistically. This recommendation was also in-line with The Five Year Forward View for Mental Health within in primary care (Mental Health Task Force, 2016).

Future Research Suggestions

Despite research highlighting information needs and preferences for results (Marlow et al., 2020, Symmons et al., 2021) the current research emphasised this as an ongoing issue, suggesting limited impact of any changes. Whilst gathering feedback can be valuable, it is also important to consider where this process sits on the ladder of participation (Arnstein, 1969). These ongoing difficulties suggest benefits of future research from a co-designing or co-producing perspective, where researchers work in collaboration with women to create the services fit for purpose. This process has also been shown to empower people, help them to feel valued, and to understand their condition better (Brett et al., 2014). Alternatively, it would also be helpful to understand the impact on emotional or psychological distress of results provided in line with recommendations for other STIs, such as HIV (D'Angelo et al., 2021; NHS Tayside n.d.). Furthermore, it might also be beneficial to understand staff experiences of providing information to women after testing positive for hrHPV and exploring the experiences of these conversations in the current context.

As discussed above, the positioning of the current research as studying emotional experiences might have automatically suggested negative emotional impacts and therefore attracted women who resonated with this experience.

Furthermore, due to the evidence that women who feel distressed often turn to the internet, it is possible that research advertised online was more likely accessed by women who reported negative experiences. However, as was evidenced in the present study, for some women, the experience held less emotional charge. Therefore, it is logical to suggest a need to better understand the mechanisms driving different emotional responses. This will help to identify areas of need or highlight subsets of women more vulnerable to associated psychological distress.

Finally, it would be useful to understand more about the process of information sharing between dyadic couples. For example, several women in the study spoke to the process of sharing, most notably with partners or mothers, but due to the research design, we could only interpret this experience from the perspective of the women who tested positive, and their interpretation of their partners understanding. Furthermore, research on dyadic adjustment has thus far only focussed on women who have tested positive (Santos et al., 2019; Santos et al., 2020). To deepen the understanding of this relational experience, it would be beneficial to capture perspectives from both sides.

Conclusion

This research explored the emotional response to the experience of testing positive for hrHPV from a phenomenological perspective. Four major themes were identified: The narratives held about hrHPV, The experiences of the delivery of services and wider NHS relationships, The relational experience of hrHPV, and Cis-women’s accounts of testing positive for hrHPV. These results represented one of many possible interpretations, but all efforts have been made by the research team to ground these findings in the data. The findings highlighted the complexity and the nuance of the emotional experience for women, which was also influenced by the many layers of context surrounding narratives associated with hrHPV.

The results also emphasised the impact of stigma and feminisation, and the role of the NHS system in this experience, with the particularly novel findings including how women can fall between systems (e.g. concerns of eligibility for cancer specific support) and the impact of hrHPV on aspects of women's identity outside of that associated with stigma. Most notable, is the impact on sense of self both in terms of shame, but also fear of potential loss of motherhood, and a change in perception of health or life stage. Furthermore, this research highlighted the dual impact of AFAB only testing, with identified consequences for women in terms of associated burden but also for AMAB in terms of denied access to knowledge, sense of sexual responsibility and possibly also necessary healthcare.

These findings emphasised a need for consideration of how hrHPV is described or positioned, the experience of the pathway for screening, receiving results, and support, and the potential impact of AFAB only testing within the NHS. It also highlighted the possible importance of better integration between psychological services and physical health, to provide additional support to those who experience intense distress.

Final Reflections

Writing this thesis has been one of the most difficult projects I have undertaken, for many reasons, but mostly because of my positioning and connection to the research alongside additional factors which further complicated my relationship to physical health. There has been a sense of symmetry during the process between myself and my participants, with impacts highlighted on identity and sense of self in particular which have been echoed in my own life, albeit for different reasons. At times it has been difficult to sustain myself throughout this process, and there have been times when I have needed to take a step back from it.

Although this forms a necessary part to my professional career, It has also encouraged me to reflect on the level of emotional labour required to undertake a project of this measure, and if it was not for the openness, honesty and vulnerability demonstrated by my participants and EbE's, I am not sure I could say this is something I would feel able to commit to again. However, having this experience and managing to reach the point of submission has also motivated me to reflect on the level of vulnerability and commitment we expect as Clinical Psychologists of the patient's or services users we work with, further encouraging me to remember the importance of patience and understanding when supporting someone through a process of this magnitude.

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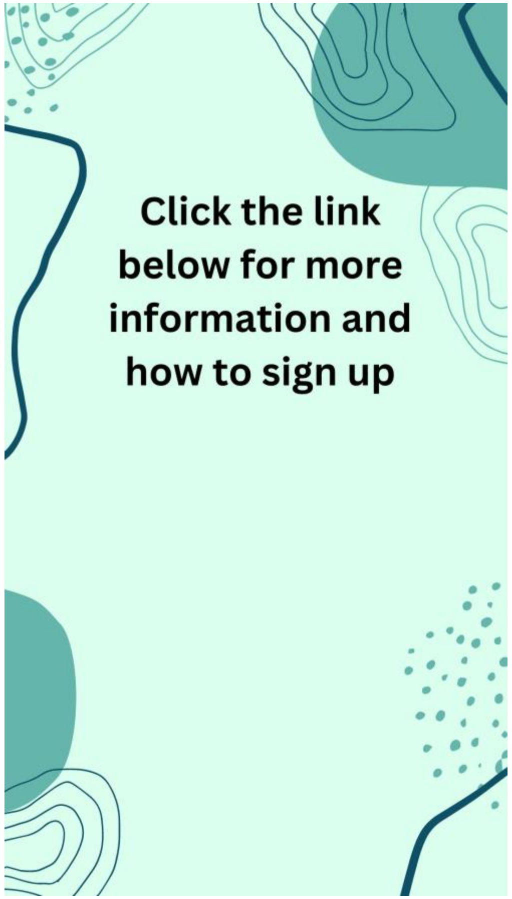
Appendix 1: Social Media Advertisements & Jo's Trust Blurb

Examples of Instagram Stories:

What is the experience of cis-women receiving a positive diagnosis of high-risk HPV via an NHS service in the UK?

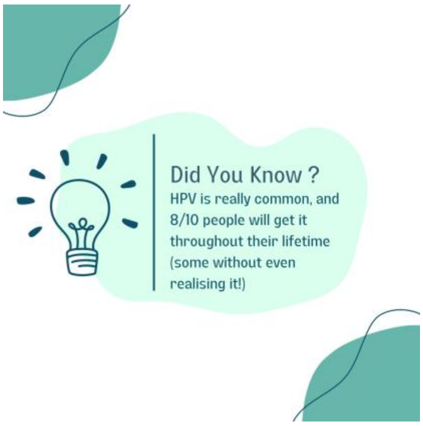
Seeking research participants

If you are a ***cis-gender woman*** who has received a ***positive diagnosis of high-risk HPV*** within the ***last 24 months*** and feels able to ***discuss this experience in detail***, we would invite you to participate.



Click the link below for more information and how to sign up

Examples of Instagram posts & caption:



Did You Know ?

HPV is really common, and 8/10 people will get it throughout their lifetime (some without even realising it!)

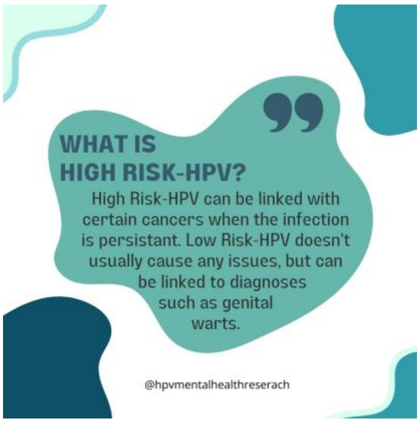
Seeking research participants

@hpvmentalhealthreserach

HPV Research

What is the experience of cis-gender women receiving a positive diagnosis of high-risk HPV via an NHS service in the UK?

@hpvmentalhealthreserach



WHAT IS HIGH RISK-HPV?

High Risk-HPV can be linked with certain cancers when the infection is persistant. Low Risk-HPV doesn't usually cause any issues, but can be linked to diagnoses such as genital warts.

@hpvmentalhealthreserach

@hpvmentalhealthresearch

Click the link in our bio for more information and how to sign up

I hope to explore how you make sense of the experience and what meaning this holds for you personally. This interpretation hopes to help identify where further emotional support may be helpful for cis-gender women in the UK.

Are you:

- A cis-gender woman who has been diagnosed with high-risk HPV in the last 24 months via the NHS for the first time?
- Able to recall this experience in detail and willing to attend a 60-90 minute interview?
- Over 18 and fluent in English?

Are there any restrictions to taking part?

- You must not have received a diagnosis of low-risk HPV.
- You must not have received multiple diagnoses of high-risk HPV where your body has cleared the virus (e.g. indicated by a negative smear result after receiving a positive result) before contracting the virus an additional time, leading to a new diagnosis. If you have received multiple positive test results from the same infection (e.g. 12 months apart), you are still eligible to take part.
- You must not have been diagnosed with Cervical Cancer or another gynaecological illness that has a direct and significant impact on your experience of HPV.
- You must not have received treatment for abnormal cervical cells (e.g. Large loop excision of the transformation zone (LLETZ)).

If you want to take part, or find out more information please email me at: S.Curzons@herts.ac.uk ***or send me a DM***

Jo's Trust Blurb:

Are you:

- A cis-gender woman who has been diagnosed with high-risk HPV in the last 24 months via the NHS for the first time?
- Able to recall this experience in detail and willing to attend a 60-90 minute interview?
- Over 18 and fluent in English?

Researchers at the University of Hertfordshire hope to explore how you make sense of this experience and what meaning this holds for you personally. The interpretation hopes to help identify where further emotional support may be helpful for cis-gender women in the UK.

Are there any restrictions to taking part?

- You must not have received a diagnosis of low-risk HPV.
- You Must not have received multiple diagnoses of high-risk HPV where your body has cleared the virus (e.g. indicated by a negative smear result after receiving a positive result) before contracting the virus an additional time, leading to a new diagnosis. If you have received multiple positive test results from the same infection (e.g. 12 months apart), you are still eligible to take part.
- You must not have been diagnosed with Cervical Cancer or another gynaecological illness that has a direct and significant impact on your experience of HPV.
- You must not have received treatment for abnormal cervical cells (e.g. Large loop excision of the transformation zone (LLETZ)).

If you want to take part, or find out more information please email me at: **S.Curzons@herts.ac.uk**

Appendix 2: Copy of Ethics Approval

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

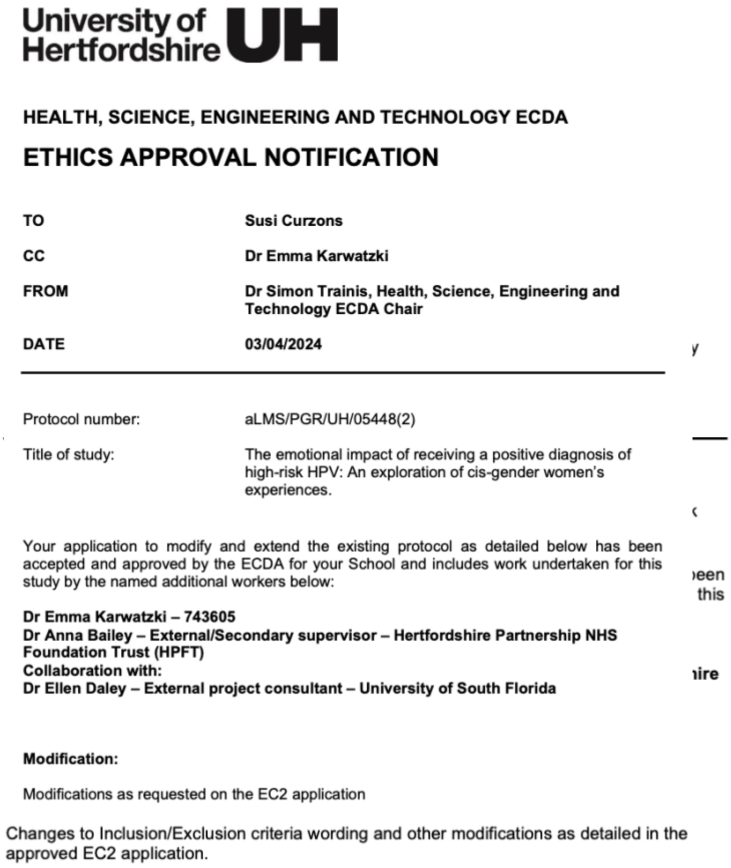
ETHICS APPROVAL NOTIFICATION

TO	**Susi Curzons**
CC	**Dr Emma Karwatzki**
FROM	**Rebecca PhD, Health, Science, Engineering and Technology ECDA Vice Chair**
DATE	**22/08/2023**

Protocol number:	LMS/PGR/UH/05448
Title of study:	The emotional impact of receiving a positive diagnosis of high-risk HPV: An exploration of cis-gender women's experiences

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Emma Karwatzki – 743605
Dr Anna Bailey – External/Secondary supervisor – Hertfordshire Partnership NHS Foundation Trust (HPFT)
Collaboration with:
Dr Ellen Daley – External project consultant – University of South Florida



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	**Susi Curzons**
CC	**Dr Emma Karwatzki**
FROM	**Dr Simon Trainis, Health, Science, Engineering and Technology ECDA Chair**
DATE	**03/04/2024**

Protocol number:	aLMS/PGR/UH/05448(2)
Title of study:	The emotional impact of receiving a positive diagnosis of high-risk HPV: An exploration of cis-gender women's experiences.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

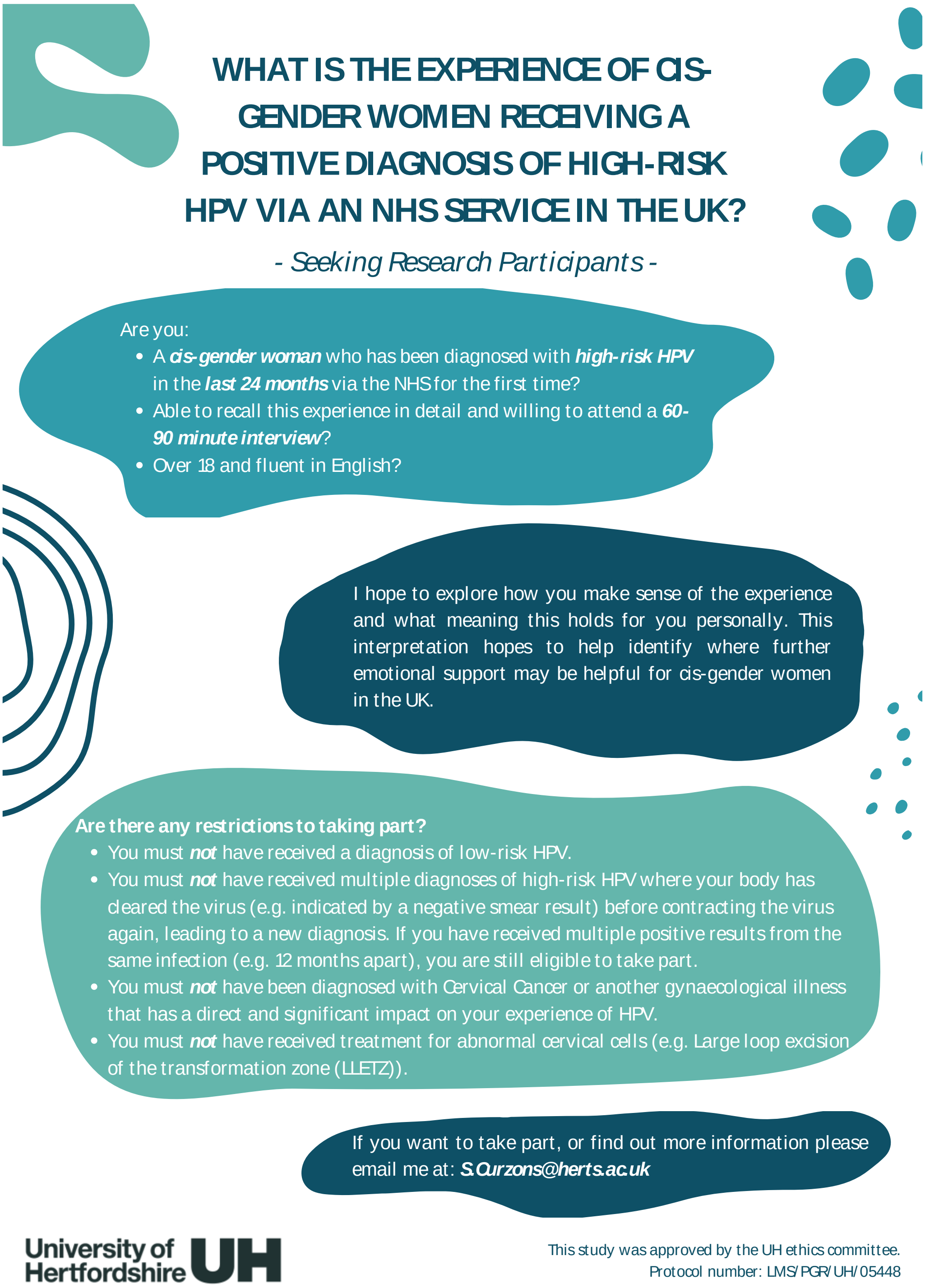
Dr Emma Karwatzki – 743605
Dr Anna Bailey – External/Secondary supervisor – Hertfordshire Partnership NHS Foundation Trust (HPFT)
Collaboration with:
Dr Ellen Daley – External project consultant – University of South Florida

Modification:

Modifications as requested on the EC2 application

Changes to Inclusion/Exclusion criteria wording and other modifications as detailed in the approved EC2 application.

Appendix 3: Recruitment Poster



WHAT IS THE EXPERIENCE OF CIS-GENDER WOMEN RECEIVING A POSITIVE DIAGNOSIS OF HIGH-RISK HPV VIA AN NHS SERVICE IN THE UK?

- Seeking Research Participants -

Are you:

- A ***cis-gender woman*** who has been diagnosed with ***high-risk HPV*** in the ***last 24 months*** via the NHS for the first time?
- Able to recall this experience in detail and willing to attend a ***60-90 minute interview***?
- Over 18 and fluent in English?

I hope to explore how you make sense of the experience and what meaning this holds for you personally. This interpretation hopes to help identify where further emotional support may be helpful for cis-gender women in the UK.

Are there any restrictions to taking part?

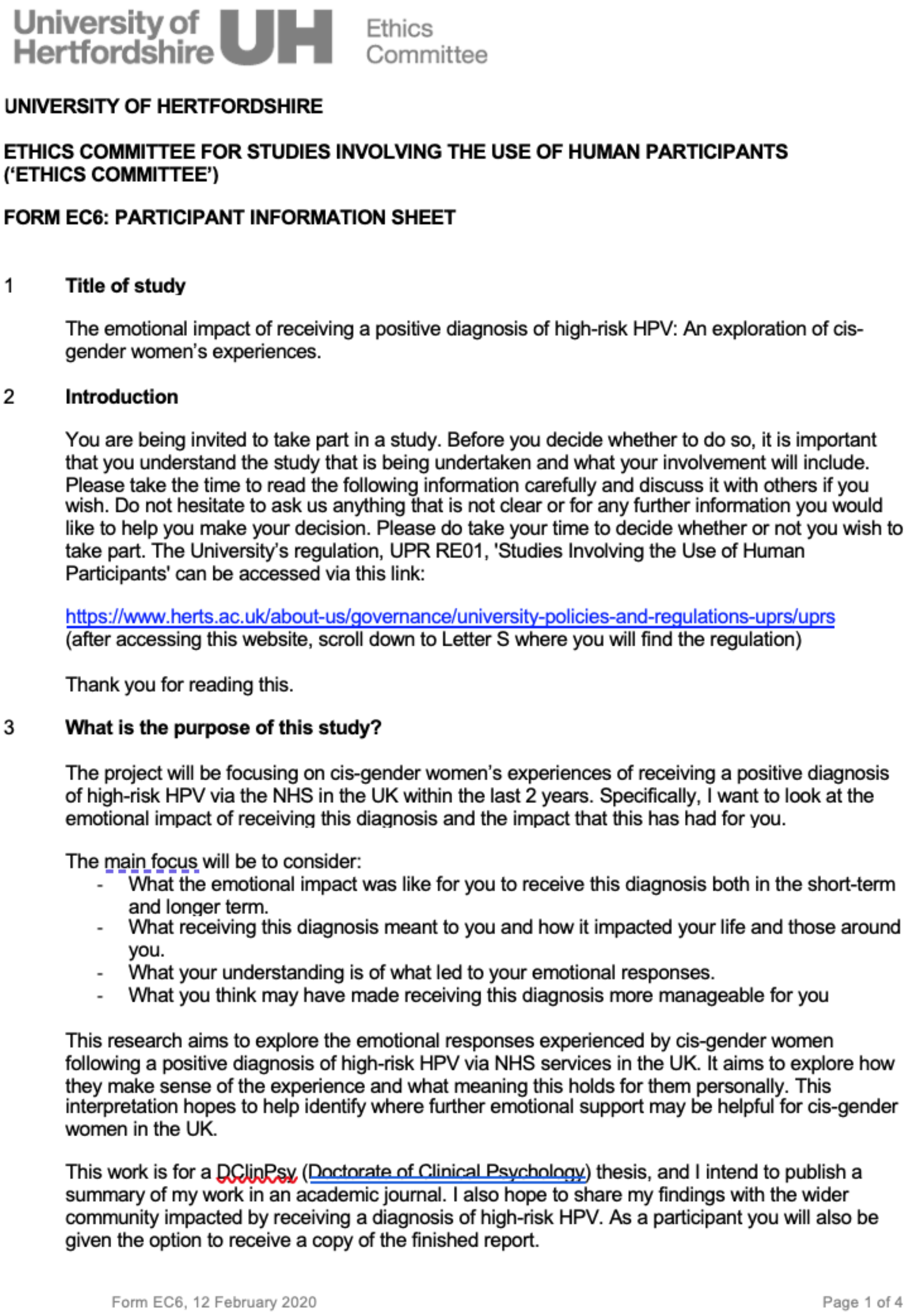
- You must ***not*** have received a diagnosis of low-risk HPV.
- You must ***not*** have received multiple diagnoses of high-risk HPV where your body has cleared the virus (e.g. indicated by a negative smear result) before contracting the virus again, leading to a new diagnosis. If you have received multiple positive results from the same infection (e.g. 12 months apart), you are still eligible to take part.
- You must ***not*** have been diagnosed with Cervical Cancer or another gynaecological illness that has a direct and significant impact on your experience of HPV.
- You must ***not*** have received treatment for abnormal cervical cells (e.g. Large loop excision of the transformation zone (LLETZ)).

If you want to take part, or find out more information please email me at: ***S.Curzons@herts.ac.uk***

University of Hertfordshire UH

This study was approved by the UH ethics committee.
Protocol number: LMS/PGR/UH/05448

Appendix 4: Participant Information Sheet



UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

1 Title of study

The emotional impact of receiving a positive diagnosis of high-risk HPV: An exploration of cis-gender women's experiences.

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

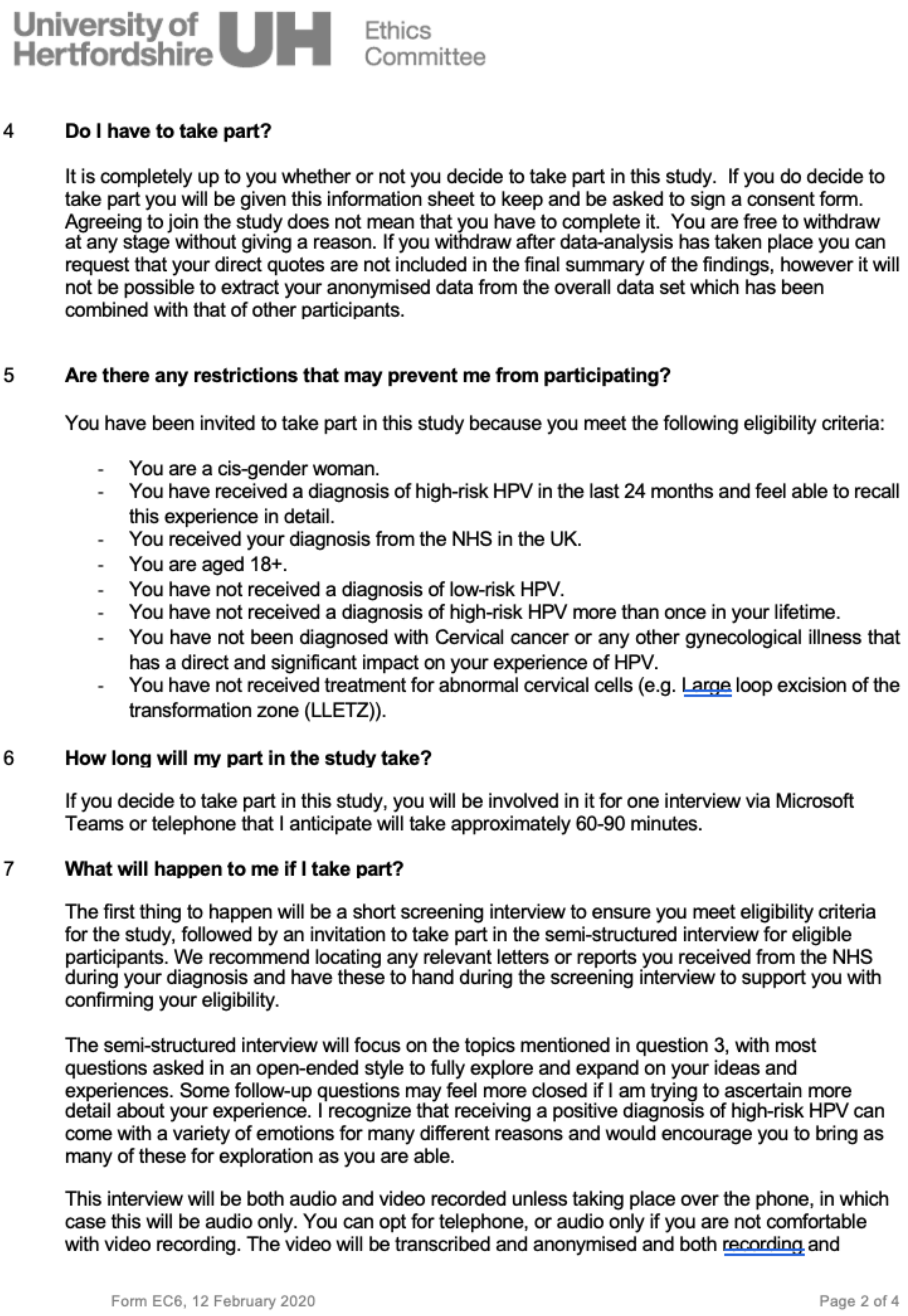
3 What is the purpose of this study?

The project will be focusing on cis-gender women's experiences of receiving a positive diagnosis of high-risk HPV via the NHS in the UK within the last 2 years. Specifically, I want to look at the emotional impact of receiving this diagnosis and the impact that this has had for you.

The main focus will be to consider:
- What the emotional impact was like for you to receive this diagnosis both in the short-term and longer term.
- What receiving this diagnosis meant to you and how it impacted your life and those around you.
- What your understanding is of what led to your emotional responses.
- What you think may have made receiving this diagnosis more manageable for you

This research aims to explore the emotional responses experienced by cis-gender women following a positive diagnosis of high-risk HPV via NHS services in the UK. It aims to explore how they make sense of the experience and what meaning this holds for them personally. This interpretation hopes to help identify where further emotional support may be helpful for cis-gender women in the UK.

This work is for a DClinPsy (Doctorate of Clinical Psychology) thesis, and I intend to publish a summary of my work in an academic journal. I also hope to share my findings with the wider community impacted by receiving a diagnosis of high-risk HPV. As a participant you will also be given the option to receive a copy of the finished report.



University of Hertfordshire UH Ethics Committee

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. If you withdraw after data-analysis has taken place you can request that your direct quotes are not included in the final summary of the findings, however it will not be possible to extract your anonymised data from the overall data set which has been combined with that of other participants.

5 Are there any restrictions that may prevent me from participating?

You have been invited to take part in this study because you meet the following eligibility criteria:

- You are a cis-gender woman.
- You have received a diagnosis of high-risk HPV in the last 24 months and feel able to recall this experience in detail.
- You received your diagnosis from the NHS in the UK.
- You are aged 18+.
- You have not received a diagnosis of low-risk HPV.
- You have not received a diagnosis of high-risk HPV more than once in your lifetime.
- You have not been diagnosed with Cervical cancer or any other gynecological illness that has a direct and significant impact on your experience of HPV.
- You have not received treatment for abnormal cervical cells (e.g. Large loop excision of the transformation zone (LLETZ)).

6 How long will my part in the study take?

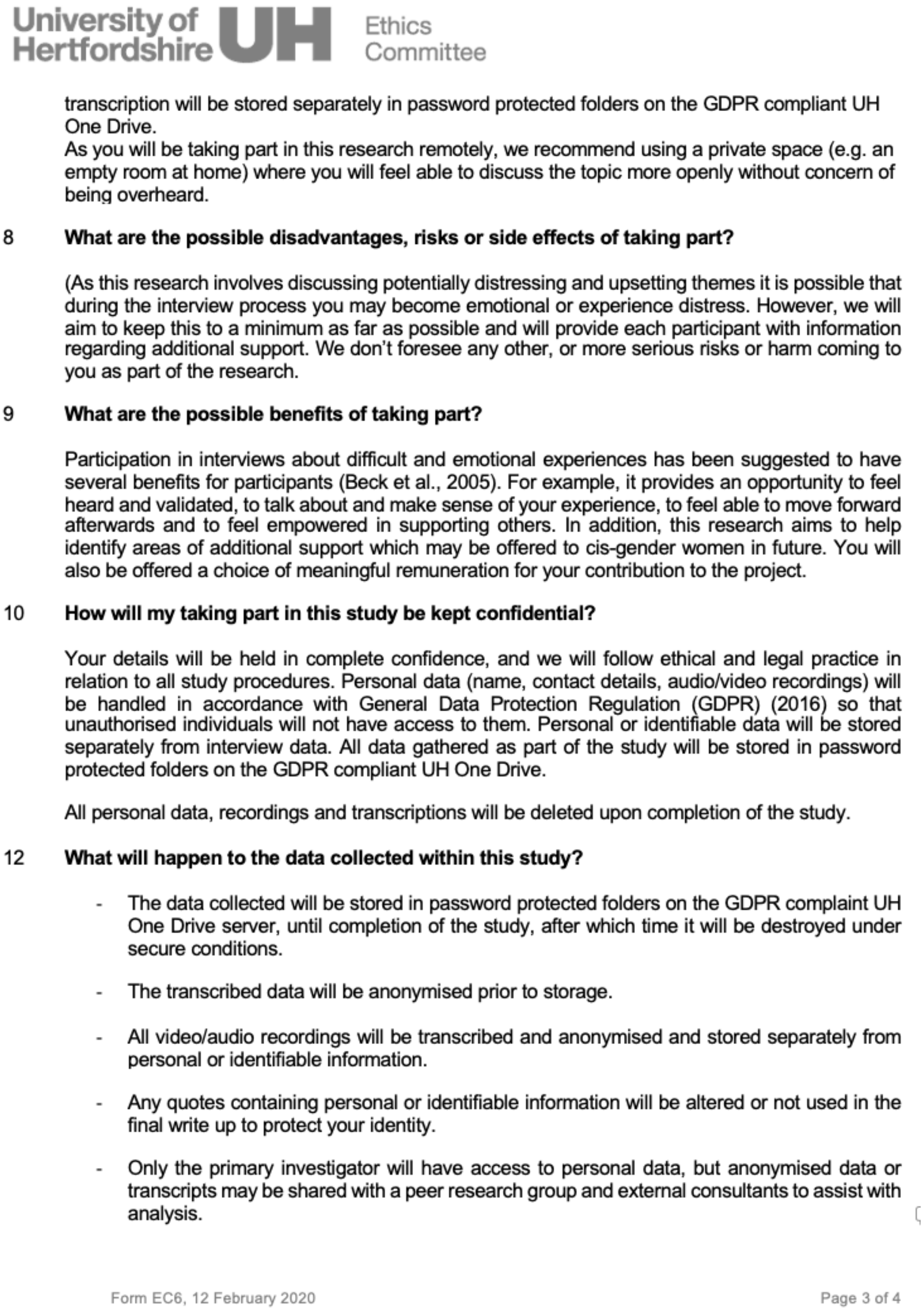
If you decide to take part in this study, you will be involved in it for one interview via Microsoft Teams or telephone that I anticipate will take approximately 60-90 minutes.

7 What will happen to me if I take part?

The first thing to happen will be a short screening interview to ensure you meet eligibility criteria for the study, followed by an invitation to take part in the semi-structured interview for eligible participants. We recommend locating any relevant letters or reports you received from the NHS during your diagnosis and have these to hand during the screening interview to support you with confirming your eligibility.

The semi-structured interview will focus on the topics mentioned in question 3, with most questions asked in an open-ended style to fully explore and expand on your ideas and experiences. Some follow-up questions may feel more closed if I am trying to ascertain more detail about your experience. I recognize that receiving a positive diagnosis of high-risk HPV can come with a variety of emotions for many different reasons and would encourage you to bring as many of these for exploration as you are able.

This interview will be both audio and video recorded unless taking place over the phone, in which case this will be audio only. You can opt for telephone, or audio only if you are not comfortable with video recording. The video will be transcribed and anonymised and both recording and



transcription will be stored separately in password protected folders on the GDPR compliant UH One Drive.
As you will be taking part in this research remotely, we recommend using a private space (e.g. an empty room at home) where you will feel able to discuss the topic more openly without concern of being overheard.

8 What are the possible disadvantages, risks or side effects of taking part?

(As this research involves discussing potentially distressing and upsetting themes it is possible that during the interview process you may become emotional or experience distress. However, we will aim to keep this to a minimum as far as possible and will provide each participant with information regarding additional support. We don't foresee any other, or more serious risks or harm coming to you as part of the research.

9 What are the possible benefits of taking part?

Participation in interviews about difficult and emotional experiences has been suggested to have several benefits for participants (Beck et al., 2005). For example, it provides an opportunity to feel heard and validated, to talk about and make sense of your experience, to feel able to move forward afterwards and to feel empowered in supporting others. In addition, this research aims to help identify areas of additional support which may be offered to cis-gender women in future. You will also be offered a choice of meaningful remuneration for your contribution to the project.

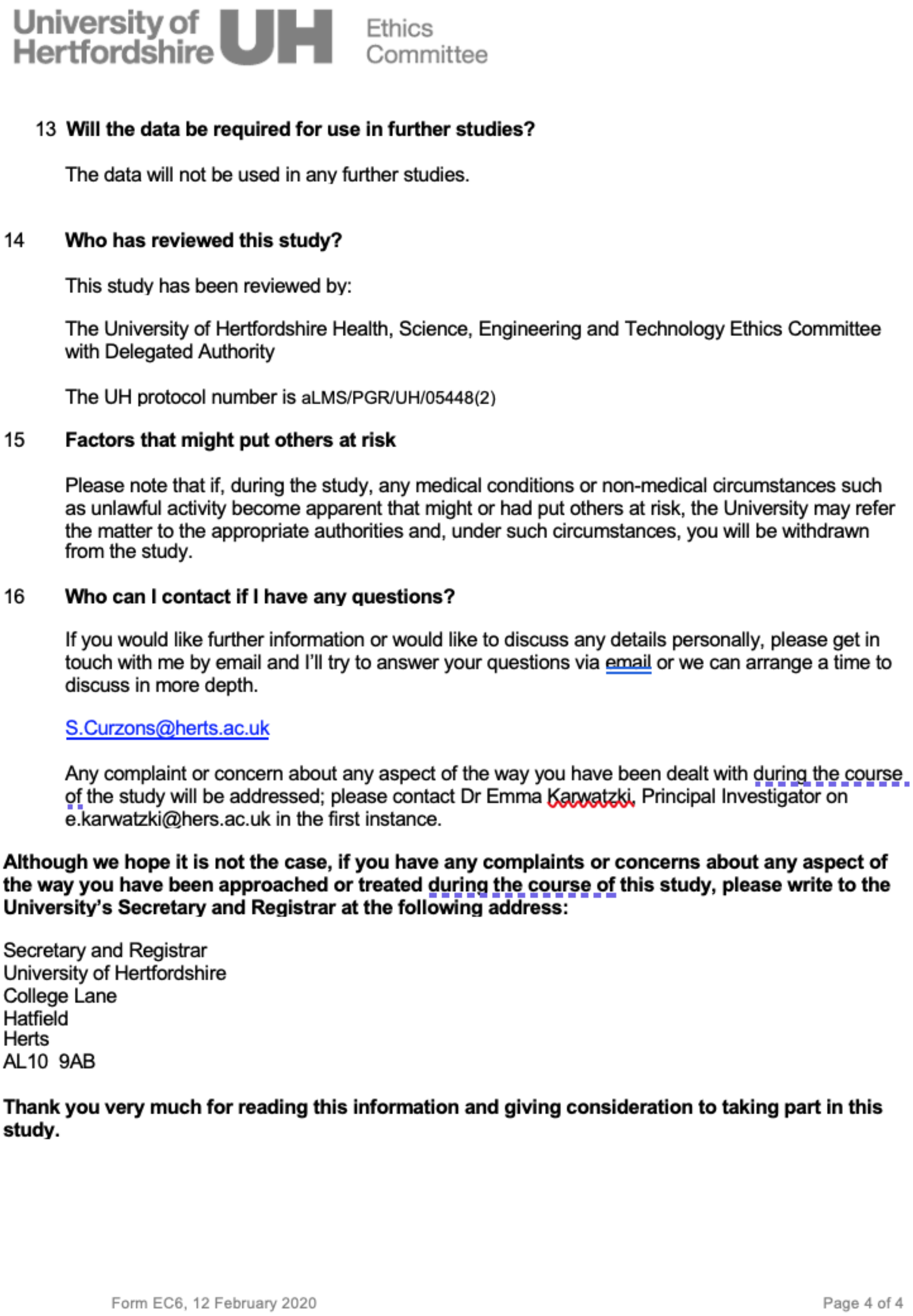
10 How will my taking part in this study be kept confidential?

Your details will be held in complete confidence, and we will follow ethical and legal practice in relation to all study procedures. Personal data (name, contact details, audio/video recordings) will be handled in accordance with General Data Protection Regulation (GDPR) (2016) so that unauthorised individuals will not have access to them. Personal or identifiable data will be stored separately from interview data. All data gathered as part of the study will be stored in password protected folders on the GDPR compliant UH One Drive.

All personal data, recordings and transcriptions will be deleted upon completion of the study.

12 What will happen to the data collected within this study?

- The data collected will be stored in password protected folders on the GDPR complaint UH One Drive server, until completion of the study, after which time it will be destroyed under secure conditions.
- The transcribed data will be anonymised prior to storage.
- All video/audio recordings will be transcribed and anonymised and stored separately from personal or identifiable information.
- Any quotes containing personal or identifiable information will be altered or not used in the final write up to protect your identity.
- Only the primary investigator will have access to personal data, but anonymised data or transcripts may be shared with a peer research group and external consultants to assist with analysis.



University of Hertfordshire UH Ethics Committee

13 **Will the data be required for use in further studies?**

The data will not be used in any further studies.

14 **Who has reviewed this study?**

This study has been reviewed by:

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is aLMS/PGR/UH/05448(2)

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by email and I'll try to answer your questions via email or we can arrange a time to discuss in more depth.

S.Curzons@herts.ac.uk

Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact Dr Emma Karwatzki, Principal Investigator on e.karwatzki@hers.ac.uk in the first instance.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Form EC6, 12 February 2020 Page 4 of 4

Appendix 5: Consent Form

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……

of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]*

……
hereby freely agree to take part in the study: The emotional impact of receiving a positive diagnosis of high-risk HPV: An exploration of cis-gender women's experiences.

UH Protocol number: aLMS/PGR/UH/05448(2)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason. I understand that if I withdraw after data-analysis has taken place that I can request that my direct quotes are not referenced, but my anonymised data will not be withdrawn from the overall data set which has been combined with that of other participants.

3 In giving my consent to participate in this study, I understand that taking part in the project will include being interviewed, and that this interview will be audio ans/or video recorded.

4 I have been given information about the risks of taking part in the study, and understand that whilst it is unlikely I will experience adverse effects there is a potential of the interview leading to emotional distress. I understand I will be given information on how to seek further support as part of the debrief.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used, including the possibility of anonymised data being combined with that in future studies.

6 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 named in these outputs unless I specifically request this.

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

University of Hertfordshire UH Ethics Committee

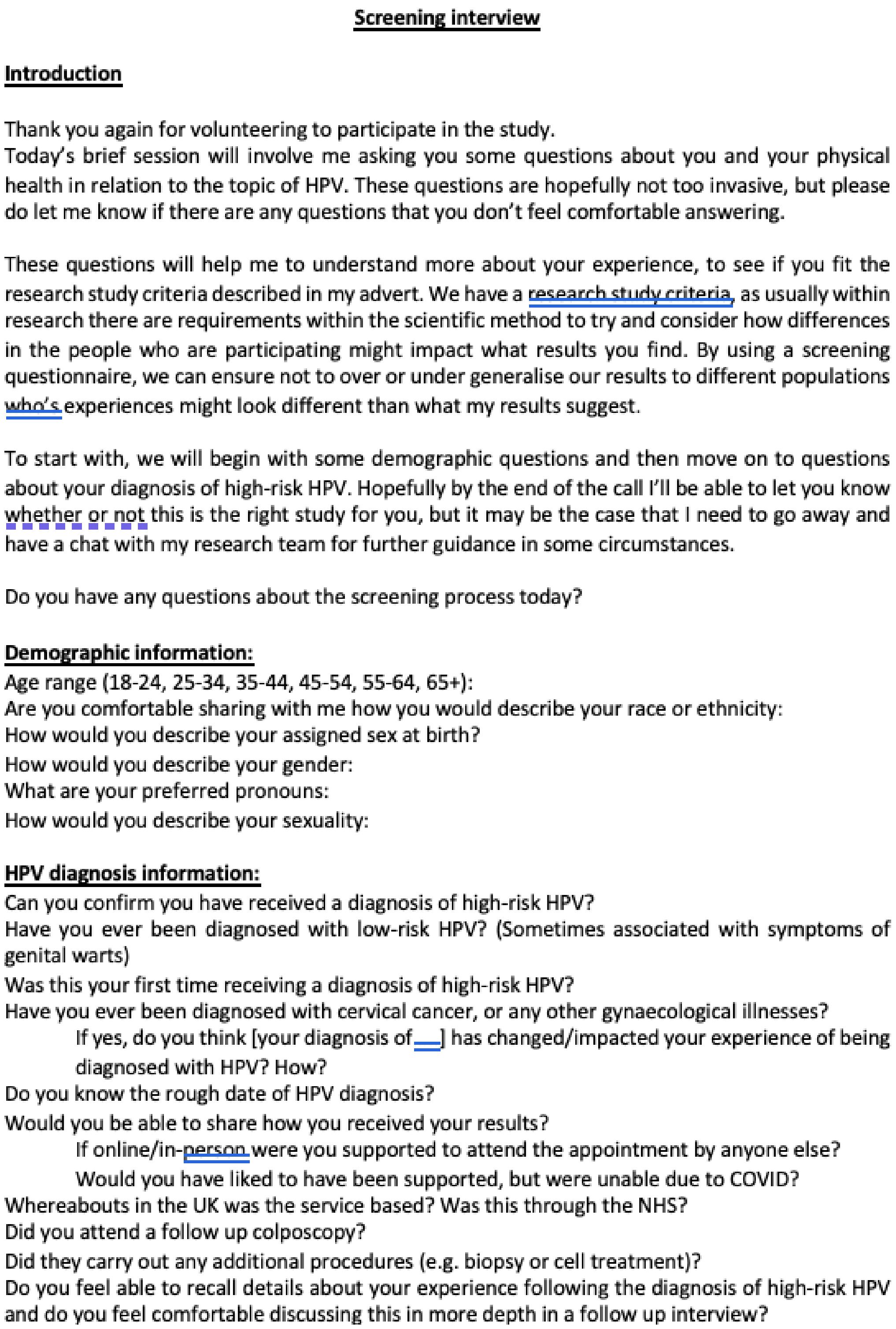
Signature of participant…………………………………………Date…………………………

Signature of (principal)
investigator………………………………………………………Date…………………………

Name of (principal) investigator *[in BLOCK CAPITALS please]*

…….*SUSI CURZONS*…..

Appendix 6: Screening Call Script



Screening interview

Introduction

Thank you again for volunteering to participate in the study.
Today’s brief session will involve me asking you some questions about you and your physical health in relation to the topic of HPV. These questions are hopefully not too invasive, but please do let me know if there are any questions that you don’t feel comfortable answering.

These questions will help me to understand more about your experience, to see if you fit the research study criteria described in my advert. We have a research study criteria, as usually within research there are requirements within the scientific method to try and consider how differences in the people who are participating might impact what results you find. By using a screening questionnaire, we can ensure not to over or under generalise our results to different populations who’s experiences might look different than what my results suggest.

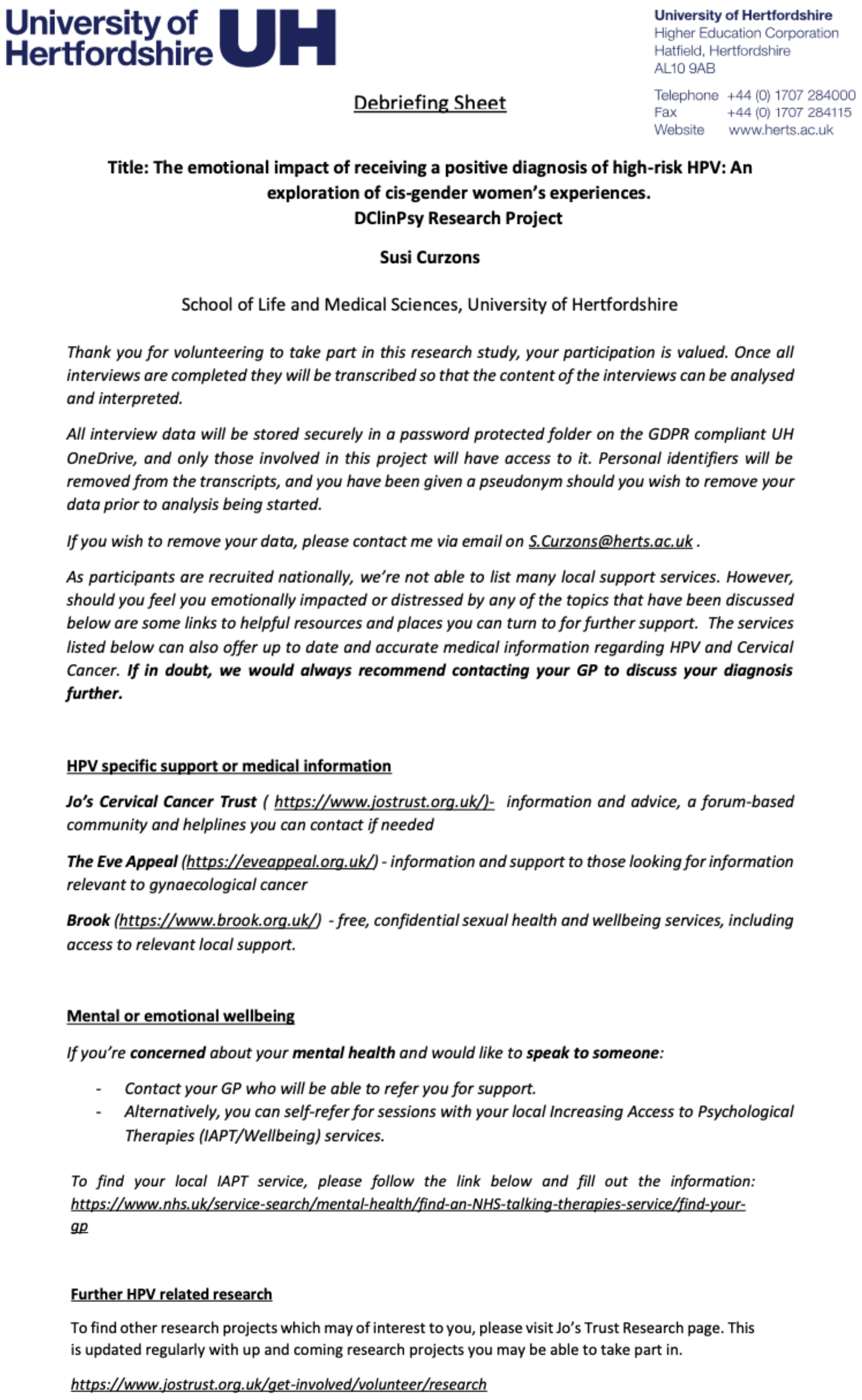
To start with, we will begin with some demographic questions and then move on to questions about your diagnosis of high-risk HPV. Hopefully by the end of the call I’ll be able to let you know whether or not this is the right study for you, but it may be the case that I need to go away and have a chat with my research team for further guidance in some circumstances.

Do you have any questions about the screening process today?

Demographic information:
Age range (18-24, 25-34, 35-44, 45-54, 55-64, 65+):
Are you comfortable sharing with me how you would describe your race or ethnicity:
How would you describe your assigned sex at birth?
How would you describe your gender:
What are your preferred pronouns:
How would you describe your sexuality:

HPV diagnosis information:
Can you confirm you have received a diagnosis of high-risk HPV?
Have you ever been diagnosed with low-risk HPV? (Sometimes associated with symptoms of genital warts)
Was this your first time receiving a diagnosis of high-risk HPV?
Have you ever been diagnosed with cervical cancer, or any other gynaecological illnesses?
    If yes, do you think [your diagnosis of __] has changed/impacted your experience of being diagnosed with HPV? How?
Do you know the rough date of HPV diagnosis?
Would you be able to share how you received your results?
    If online/in-person were you supported to attend the appointment by anyone else?
    Would you have liked to have been supported, but were unable due to COVID?
Whereabouts in the UK was the service based? Was this through the NHS?
Did you attend a follow up colposcopy?
Did they carry out any additional procedures (e.g. biopsy or cell treatment)?
Do you feel able to recall details about your experience following the diagnosis of high-risk HPV and do you feel comfortable discussing this in more depth in a follow up interview?

Appendix 7: Participant Debrief Sheet



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Website www.herts.ac.uk

Debriefing Sheet

Title: The emotional impact of receiving a positive diagnosis of high-risk HPV: An exploration of cis-gender women's experiences.
DClinPsy Research Project

Susi Curzons

School of Life and Medical Sciences, University of Hertfordshire

Thank you for volunteering to take part in this research study, your participation is valued. Once all interviews are completed they will be transcribed so that the content of the interviews can be analysed and interpreted.

All interview data will be stored securely in a password protected folder on the GDPR compliant UH OneDrive, and only those involved in this project will have access to it. Personal identifiers will be removed from the transcripts, and you have been given a pseudonym should you wish to remove your data prior to analysis being started.

If you wish to remove your data, please contact me via email on S.Curzons@herts.ac.uk .

As participants are recruited nationally, we're not able to list many local support services. However, should you feel you emotionally impacted or distressed by any of the topics that have been discussed below are some links to helpful resources and places you can turn to for further support. The services listed below can also offer up to date and accurate medical information regarding HPV and Cervical Cancer. ***If in doubt, we would always recommend contacting your GP to discuss your diagnosis further.***

HPV specific support or medical information

Jo's Cervical Cancer Trust *(https://www.jostrust.org.uk/)- information and advice, a forum-based community and helplines you can contact if needed*

The Eve Appeal *(https://eveappeal.org.uk/) - information and support to those looking for information relevant to gynaecological cancer*

Brook *(https://www.brook.org.uk/) - free, confidential sexual health and wellbeing services, including access to relevant local support.*

Mental or emotional wellbeing

If you're ***concerned*** *about your* ***mental health*** *and would like to* ***speak to someone****:*

- *Contact your GP who will be able to refer you for support.*
- *Alternatively, you can self-refer for sessions with your local Increasing Access to Psychological Therapies (IAPT/Wellbeing) services.*

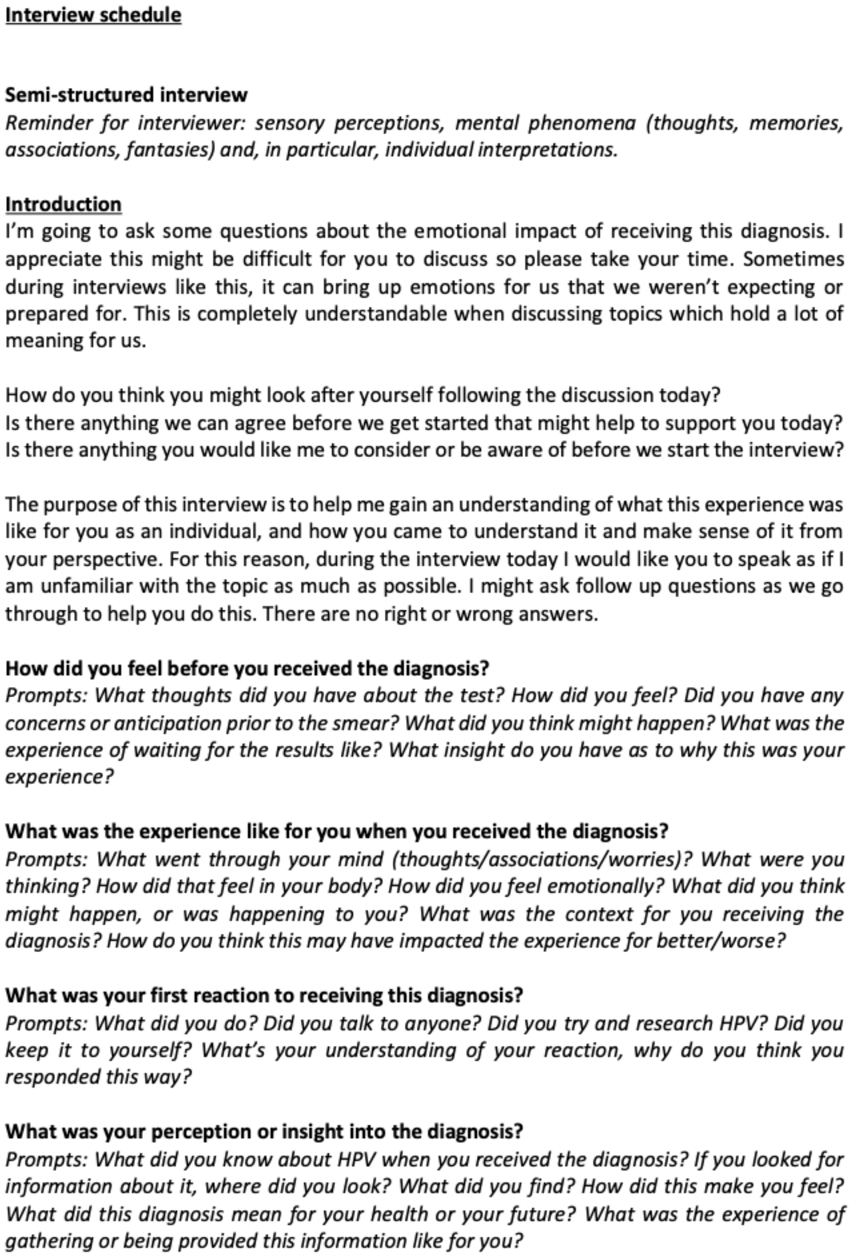
To find your local IAPT service, please follow the link below and fill out the information: https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service/find-your-gp

Further HPV related research

To find other research projects which may of interest to you, please visit Jo's Trust Research page. This is updated regularly with up and coming research projects you may be able to take part in.

https://www.jostrust.org.uk/get-involved/volunteer/research

Appendix 8: Interview Schedule



Interview schedule

Semi-structured interview

Reminder for interviewer: sensory perceptions, mental phenomena (thoughts, memories, associations, fantasies) and, in particular, individual interpretations.

Introduction

I'm going to ask some questions about the emotional impact of receiving this diagnosis. I appreciate this might be difficult for you to discuss so please take your time. Sometimes during interviews like this, it can bring up emotions for us that we weren't expecting or prepared for. This is completely understandable when discussing topics which hold a lot of meaning for us.

How do you think you might look after yourself following the discussion today?
Is there anything we can agree before we get started that might help to support you today?
Is there anything you would like me to consider or be aware of before we start the interview?

The purpose of this interview is to help me gain an understanding of what this experience was like for you as an individual, and how you came to understand it and make sense of it from your perspective. For this reason, during the interview today I would like you to speak as if I am unfamiliar with the topic as much as possible. I might ask follow up questions as we go through to help you do this. There are no right or wrong answers.

How did you feel before you received the diagnosis?

Prompts: What thoughts did you have about the test? How did you feel? Did you have any concerns or anticipation prior to the smear? What did you think might happen? What was the experience of waiting for the results like? What insight do you have as to why this was your experience?

What was the experience like for you when you received the diagnosis?

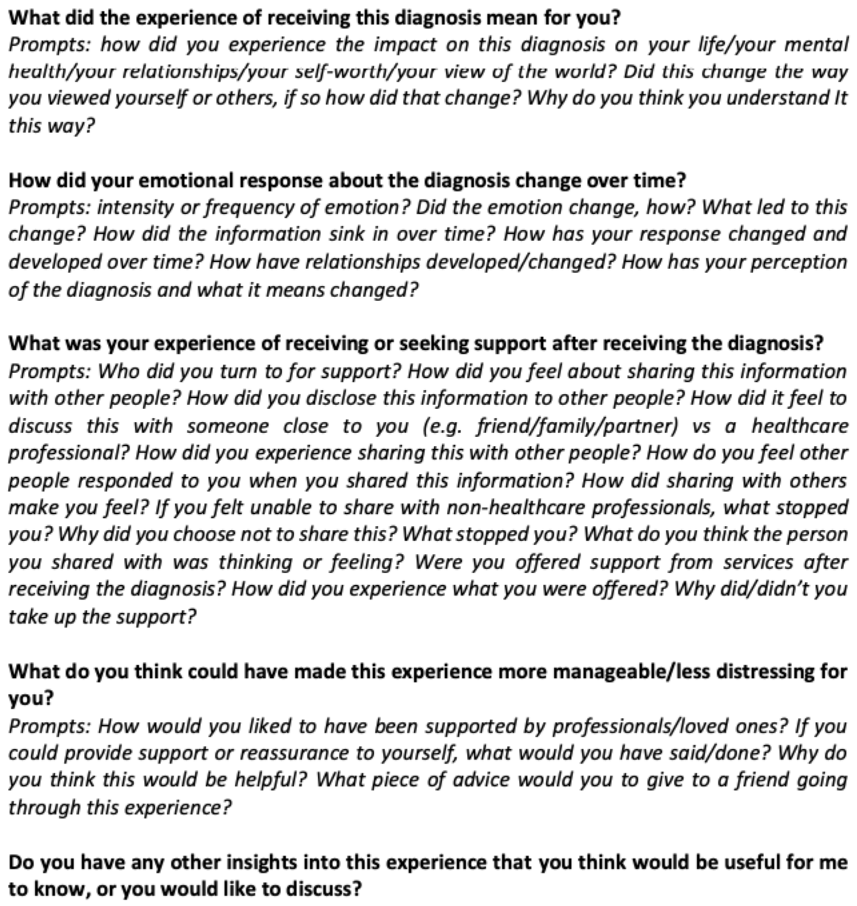
Prompts: What went through your mind (thoughts/associations/worries)? What were you thinking? How did that feel in your body? How did you feel emotionally? What did you think might happen, or was happening to you? What was the context for you receiving the diagnosis? How do you think this may have impacted the experience for better/worse?

What was your first reaction to receiving this diagnosis?

Prompts: What did you do? Did you talk to anyone? Did you try and research HPV? Did you keep it to yourself? What's your understanding of your reaction, why do you think you responded this way?

What was your perception or insight into the diagnosis?

Prompts: What did you know about HPV when you received the diagnosis? If you looked for information about it, where did you look? What did you find? How did this make you feel? What did this diagnosis mean for your health or your future? What was the experience of gathering or being provided this information like for you?



What did the experience of receiving this diagnosis mean for you?
Prompts: how did you experience the impact on this diagnosis on your life/your mental health/your relationships/your self-worth/your view of the world? Did this change the way you viewed yourself or others, if so how did that change? Why do you think you understand It this way?

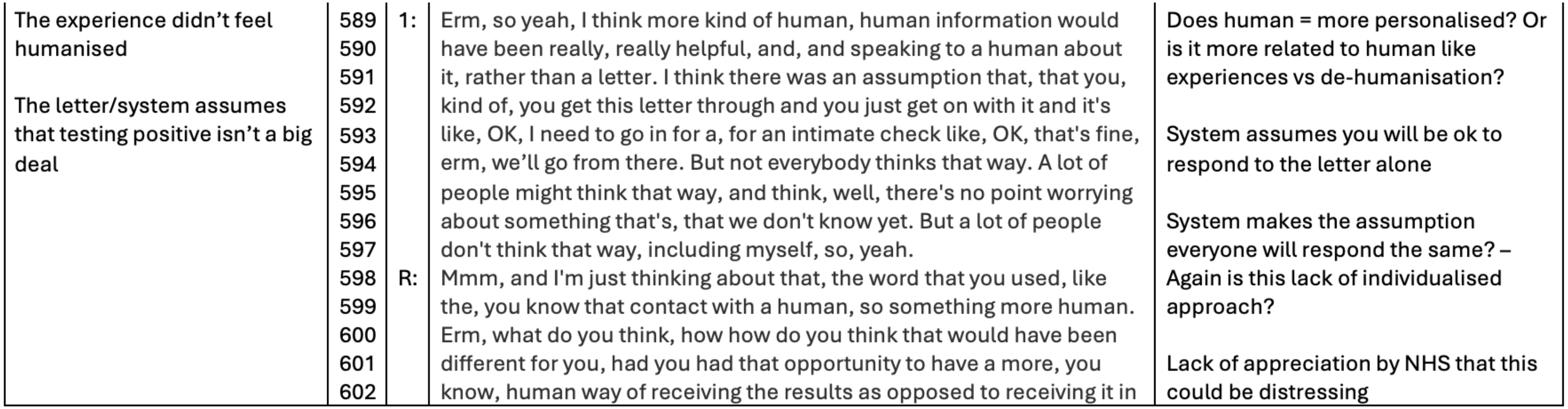
How did your emotional response about the diagnosis change over time?
Prompts: intensity or frequency of emotion? Did the emotion change, how? What led to this change? How did the information sink in over time? How has your response changed and developed over time? How have relationships developed/changed? How has your perception of the diagnosis and what it means changed?

What was your experience of receiving or seeking support after receiving the diagnosis?
Prompts: Who did you turn to for support? How did you feel about sharing this information with other people? How did you disclose this information to other people? How did it feel to discuss this with someone close to you (e.g. friend/family/partner) vs a healthcare professional? How did you experience sharing this with other people? How do you feel other people responded to you when you shared this information? How did sharing with others make you feel? If you felt unable to share with non-healthcare professionals, what stopped you? Why did you choose not to share this? What stopped you? What do you think the person you shared with was thinking or feeling? Were you offered support from services after receiving the diagnosis? How did you experience what you were offered? Why did/didn't you take up the support?

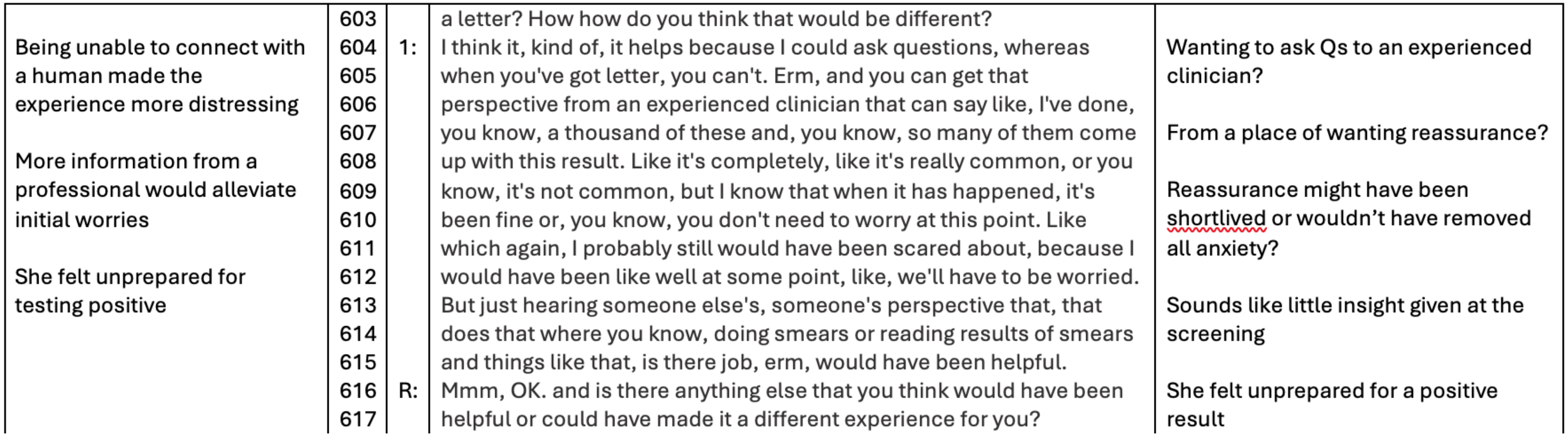
What do you think could have made this experience more manageable/less distressing for you?
Prompts: How would you liked to have been supported by professionals/loved ones? If you could provide support or reassurance to yourself, what would you have said/done? Why do you think this would be helpful? What piece of advice would you to give to a friend going through this experience?

Do you have any other insights into this experience that you think would be useful for me to know, or you would like to discuss?

Appendix 9: An Example of Exploratory Notes & Experiential Statements from Clara's Transcript

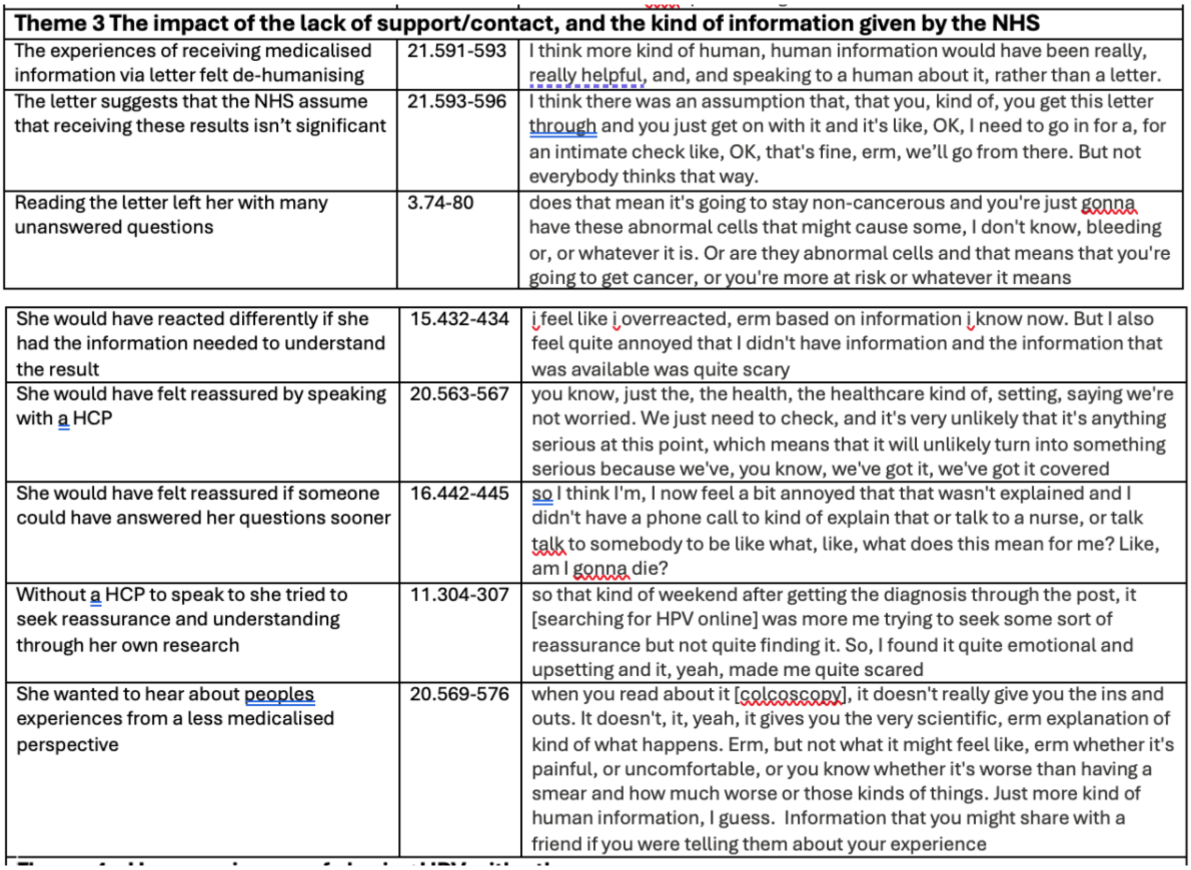


The experience didn't feel	589	1:	Erm, so yeah, I think more kind of human, human information would	Does human = more personalised? Or
humanised	590		have been really, really helpful, and, and speaking to a human about	is it more related to human like
	591		it, rather than a letter. I think there was an assumption that, that you,	experiences vs de-humanisation?
The letter/system assumes	592		kind of, you get this letter through and you just get on with it and it's	
that testing positive isn't a big	593		like, OK, I need to go in for a, for an intimate check like, OK, that's fine,	System assumes you will be ok to
deal	594		erm, we'll go from there. But not everybody thinks that way. A lot of	respond to the letter alone
	595		people might think that way, and think, well, there's no point worrying	
	596		about something that's, that we don't know yet. But a lot of people	System makes the assumption
	597		don't think that way, including myself, so, yeah.	everyone will respond the same? –
	598	R:	Mmm, and I'm just thinking about that, the word that you used, like	Again is this lack of individualised
	599		the, you know that contact with a human, so something more human.	approach?
	600		Erm, what do you think, how how do you think that would have been	
	601		different for you, had you had that opportunity to have a more, you	Lack of appreciation by NHS that this
	602		know, human way of receiving the results as opposed to receiving it in	could be distressing



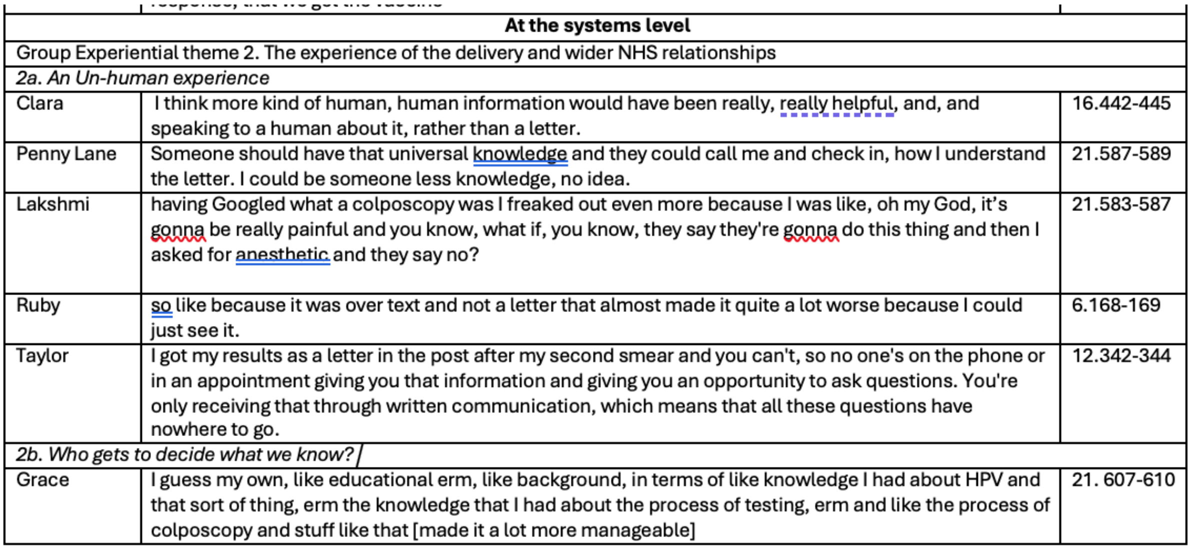
	603		a letter? How how do you think that would be different?	
Being unable to connect with	604	1:	I think it, kind of, it helps because I could ask questions, whereas	Wanting to ask Qs to an experienced
a human made the	605		when you've got letter, you can't. Erm, and you can get that	clinician?
experience more distressing	606		perspective from an experienced clinician that can say like, I've done,	
	607		you know, a thousand of these and, you know, so many of them come	From a place of wanting reassurance?
More information from a	608		up with this result. Like it's completely, like it's really common, or you	
professional would alleviate	609		know, it's not common, but I know that when it has happened, it's	Reassurance might have been
initial worries	610		been fine or, you know, you don't need to worry at this point. Like	shortlived or wouldn't have removed
	611		which again, I probably still would have been scared about, because I	all anxiety?
She felt unprepared for	612		would have been like well at some point, like, we'll have to be worried.	
testing positive	613		But just hearing someone else's, someone's perspective that, that	Sounds like little insight given at the
	614		does that where you know, doing smears or reading results of smears	screening
	615		and things like that, is there job, erm, would have been helpful.	
	616	R:	Mmm, OK. and is there anything else that you think would have been	She felt unprepared for a positive
	617		helpful or could have made it a different experience for you?	result

Appendix 10: An Example of Clara's Corresponding Personal Experiential Themes

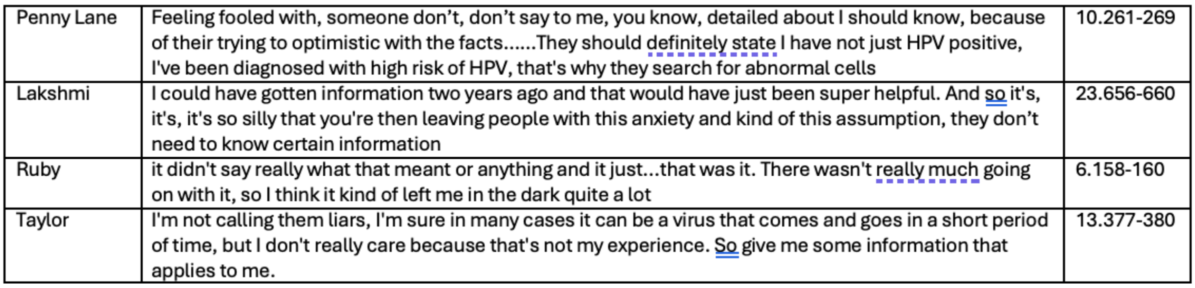


Theme 3 The impact of the lack of support/contact, and the kind of information given by the NHS		
The experiences of receiving medicalised information via letter felt de-humanising	21.591-593	I think more kind of human, human information would have been really, really helpful, and, and speaking to a human about it, rather than a letter.
The letter suggests that the NHS assume that receiving these results isn't significant	21.593-596	I think there was an assumption that, that you, kind of, you get this letter through and you just get on with it and it's like, OK, I need to go in for a, for an intimate check like, OK, that's fine, erm, we'll go from there. But not everybody thinks that way.
Reading the letter left her with many unanswered questions	3.74-80	does that mean it's going to stay non-cancerous and you're just gonna have these abnormal cells that might cause some, I don't know, bleeding or, or whatever it is. Or are they abnormal cells and that means that you're going to get cancer, or you're more at risk or whatever it means
She would have reacted differently if she had the information needed to understand the result	15.432-434	i feel like i overreacted, erm based on information i know now. But I also feel quite annoyed that I didn't have information and the information that was available was quite scary
She would have felt reassured by speaking with a HCP	20.563-567	you know, just the, the health, the healthcare kind of, setting, saying we're not worried. We just need to check, and it's very unlikely that it's anything serious at this point, which means that it will unlikely turn into something serious because we've, you know, we've got it, we've got it covered
She would have felt reassured if someone could have answered her questions sooner	16.442-445	so I think I'm, I now feel a bit annoyed that that wasn't explained and I didn't have a phone call to kind of explain that or talk to a nurse, or talk talk to somebody to be like what, like, what does this mean for me? Like, am I gonna die?
Without a HCP to speak to she tried to seek reassurance and understanding through her own research	11.304-307	so that kind of weekend after getting the diagnosis through the post, it [searching for HPV online] was more me trying to seek some sort of reassurance but not quite finding it. So, I found it quite emotional and upsetting and it, yeah, made me quite scared
She wanted to hear about peoples experiences from a less medicalised perspective	20.569-576	when you read about it [colcoscopy], it doesn't really give you the ins and outs. It doesn't, it, yeah, it gives you the very scientific, erm explanation of kind of what happens. Erm, but not what it might feel like, erm whether it's painful, or uncomfortable, or you know whether it's worse than having a smear and how much worse or those kinds of things. Just more kind of human information, I guess. Information that you might share with a friend if you were telling them about your experience

Appendix 11: An Example of Resulting Group Experiential Theme



At the systems level		
Group Experiential theme 2. The experience of the delivery and wider NHS relationships		
2a. An Un-human experience		
Clara	I think more kind of human, human information would have been really, really helpful, and, and speaking to a human about it, rather than a letter.	16.442-445
Penny Lane	Someone should have that universal knowledge and they could call me and check in, how I understand the letter. I could be someone less knowledge, no idea.	21.587-589
Lakshmi	having Googled what a colposcopy was I freaked out even more because I was like, oh my God, it's gonna be really painful and you know, what if, you know, they say they're gonna do this thing and then I asked for anesthetic and they say no?	21.583-587
Ruby	so like because it was over text and not a letter that almost made it quite a lot worse because I could just see it.	6.168-169
Taylor	I got my results as a letter in the post after my second smear and you can't, so no one's on the phone or in an appointment giving you that information and giving you an opportunity to ask questions. You're only receiving that through written communication, which means that all these questions have nowhere to go.	12.342-344
2b. Who gets to decide what we know?		
Grace	I guess my own, like educational erm, like background, in terms of like knowledge I had about HPV and that sort of thing, erm the knowledge that I had about the process of testing, erm and like the process of colposcopy and stuff like that [made it a lot more manageable]	21. 607-610



Penny Lane	Feeling fooled with, someone don't, don't say to me, you know, detailed about I should know, because of their trying to optimistic with the facts......They should definitely state I have not just HPV positive, I've been diagnosed with high risk of HPV, that's why they search for abnormal cells	10.261-269
Lakshmi	I could have gotten information two years ago and that would have just been super helpful. And so it's, it's, it's so silly that you're then leaving people with this anxiety and kind of this assumption, they don't need to know certain information	23.656-660
Ruby	it didn't say really what that meant or anything and it just...that was it. There wasn't really much going on with it, so I think it kind of left me in the dark quite a lot	6.158-160
Taylor	I'm not calling them liars, I'm sure in many cases it can be a virus that comes and goes in a short period of time, but I don't really care because that's not my experience. So give me some information that applies to me.	13.377-380

Appendix 12: Examples from Reflective Logs

What am I Drawn to within this research? Qualitative research – wanting to be able to tell women's stories. As women often we are reduced to statistics or numbers, and by using qualitative methods I would be be able to remove some of this de-humanisation through the process. Education and policy – I acknowledge that I already feel strongly that sexual health and relationship education is poorly managed in schools and wider society. I expect to find that there are perhaps links between this and emotional responses to high-risk HPV, but also need to make sure I remain reflexive and try to look for those experiences that sit outside this expectation.
When researching the impact of high-risk HPV I have been drawn to research by Dr Daley as this aligns with my perception of how HPV is frequently sold as solely a women's health issue. I am intrigued to read more related to this topic, but also conscious of the impact of an echo chamber
I did my pilot interview today and came away from it feeling a bit rushed and like I did not always follow up with the right concepts. I was also conscious of not wanting to disturb the rapport with one of my EbEs and so perhaps held back from asking some more probing questions on particular topics. I need to remember the others skillsets I have developed throughout training and remember to drawn on abilities to help contain distressing emotions, and sitting with the silences or pauses to allow deeper thought. Another thought, is to focus more on questioning where an answer might be assumed, I need to make sure I am not assuming I understand based on my own thoughts and experiences. Finally, I did not feel like I knew the schedule well enough, which perhaps interfered with the flow of the line of questioning.
I struggled with this interview and wonder if this was because I was struggling to find a mutual understanding of the experience in the moment. I also realised part

way through I had somewhat deviated from the interview schedule. I think I was struggling to push her responses towards an emotional reaction, possibly because I was aware of the recency of her results. I also felt a sense of reluctancy from her to uncover aspects of experience in more depth. So I decided to use my clinical judgement to take a step back in these instances and allow the interview to be more driven by what she wanted to bring. I was also aware that at times I helped her to name some emotions she wasn't quite sure of, and now wonder what impact this might have on my understanding of her sense-making.