

# A Quantum of Solace

An Exploratory Mixed Methods Study of Online Support in  
the Self-Management of Anxiety in HPV Positive Women

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## **Abstract**

*Background:* The implementation of human papillomavirus (HPV) DNA detection as the primary screening tool for screening and management of cervical intraepithelial neoplasia (CIN) proposed for roll-out in 2019-2020 will diagnose more women as HPV positive than are currently diagnosed with CIN due to the relative differences in prevalence between conditions (Sargent et al. 2008; Peto et al. 2004). At present there is no acceptable treatment for HPV (McRae et al. 2014). Anxiety over positivity (Friedman & Sheppard 2007), stigma (Kim 2012), and uncertainty (Kosenko et al. 2012) may constitute a biographical disruption. The stigmatised nature of HPV mean support from regular channels may be restricted due to fears of social rejection following disclosure (Kosenko et al. 2012; Crandall & Moriarty 1995). Online support might instead be utilised to allow access to disease information and social support.

*Methods:* The study was a mixed methods study based on the follow-up explanations model, involving the administration of an online survey questionnaire (N = 107). Following descriptive data analysis, individuals were recruited for email interviews to describe their lived experiences of HPV positivity (N = 3). These narratives were then analysed using thematic analysis.

*Findings:* Women responding to the questionnaire and the interviews reported anxiety over fears of transmission to loved ones. Interview narratives disclosed themes of anxiety caused by the mismanagement of information (too much/too little, conflicting or given at the wrong moment), uncertainty over viral clearance and residual issues of stigma. Women reported the use of online support to exchange information and experiences and provide emotional support.

*Conclusions:* Both the questionnaire and the interview data indicate that uncertainty, anxiety over cancer development and guilt over transmission constitute a biographical disruption among women aware of their HPV positive status, and that the use of online support may be helpful in managing the uncertainty of HPV positivity.



## **Chapter One**

### **1.1. Introduction**

The introduction of human papillomavirus testing as the primary screening method may constitute a change to the social context of cervical screening. This chapter will commence with a synopsis of the study and introduce the research problem by examining the prevalence of the human papillomavirus and cervical intraepithelial neoplasia and the current use of human papillomavirus testing in the NHS cervical screening programme. Background literature examining the biomedical aspects of cervical screening including the aetiology and epidemiology of cervical cancer and the public awareness of screening will then be discussed.

### **1.2. Synopsis of the Study**

The study adopted a mixed methods approach, utilising a combination of questionnaires and semi-structured online interviews. A questionnaire was utilised to obtain descriptive data regarding the characteristics of an online support population, and online interviews were used to add depth and explanatory data to this description (Ivankova et al. 2006). The questionnaire aimed to examine the demographic and usage characteristics of women using or subscribing to human papillomavirus (HPV)- and cervical cancer-related online resources such as internet forums and online support groups, while the semi-structured online interviews were employed to gain insight into the day-to-day lived experiences of the diagnostic and treatment arc, of HPV positivity and/or cervical cancer or pre-cancer as a biographical disruption, and the role that online support groups play in the meaning-making processes and biographical renegotiation of affected women.

Following the gathering of questionnaire data, participants were recruited from HPV-specific online and social media platforms and invited to participate in semi-structured online interviews, in order to obtain data pertaining to individuals' views on the reality of HPV positivity and their online informational and support needs. Transcripts from these interviews were then analysed using thematic analysis in order to understand the meanings these users applied to both the condition of HPV positivity and any benefits derived from sharing information and emotional support with other users (Oliver et al. 2015; Hu et al. 2012; Powell et al. 2011; Beaudoin & Tao 2008).

### **1.3. Statement of the Research Problem**

In 1999 a five site multicentre study established that the human papillomavirus (HPV) was a "necessary cause of cervical cancer worldwide" (Walboomers et al. 1999). The authors concluded from their findings that, in combination with data from a 1995 paper and the IARC monograph of the same year (Bosch & Manos 1995; IARC 1995), molecular evidence of HPV was found in 99.7% of some 869 biopsies that the group examined. Research into HPV DNA detection methods had already been ongoing for some years (Schiffman 1992; Schiffman et al. 1991; van den Brule et al. 1990) allowing for the classification of HPV subtypes into 'high' and 'low' risk according to their oncogenic potential (Doorbar et al. 2012). However, the identification of a single, necessary cause for cervical cancer also allowed for the concept that the disease might be preventable through vaccination. Similar to virus detection studies, research into the development of a vaccine in animal models had been ongoing since the late 1990s (Suzich et al. 1995) and results of the first human trials of vaccine models were published from 2004 (Harper et al. 2006; Villa et al. 2005; Harper et al. 2004).

Following the publication of outcomes from the TOMBOLA trial (Cotton et al. 2006; 2010), recommendations from the 2007 Cancer Reform Strategy (DoH 2007) and early outcomes from the ARTISTIC trial (Albrow et al. 2012; Kitchener et al. 2011; Kelly et al. 2011; Kitchener & Walker 2008) the UK National Screening Committee (UK NSC) made recommendations to the four UK Governments (of England, Scotland, Wales and Northern Ireland) to implement molecular testing for high-risk human papillomavirus (HR-HPV) nucleic acids in cervical cytology samples. HPV testing is used to triage the cervical cytology samples of women who demonstrate a cytologic borderline or low grade abnormality by microscopy (Kitchener et al. 2009; Howard et al. 2008), and as a triage tool for previously untreated, biopsy-proven low-grade cervical intraepithelial neoplasia (clinically termed CIN1) – these triage tests are known as ‘triage-untreated’ (TUT). Additionally, HR-HPV DNA or RNA testing is used as a follow-up test at six months post-treatment as a ‘test-of-cure’ (TOC) – in the case of HPV negativity these women are returned to normal 3- or 5- year screening intervals (dependent on age) where they would have previously been on annual cytological surveillance for ten years (NHS Cancer Screening Programmes 2011). In England, the current implementation of HR-HPV testing (for triage, TUT and TOC) is an interim measure – as of January 2016, Public Health England (PHE) announced that the UK NSC had recommended that PHE implement the use of molecular detection of HR-HPV DNA/RNA as a primary screening tool, using microscopy as an adjunct test in the case of HR-HPV positivity (PHE 2016b).

However, a change to the screening method is likely to impact and alter the social and cultural context of cervical screening. Cervical screening will subsequently change from its current form – a biomedical test that examines for the presence of a treatable condition (pre-malignant intraepithelial neoplasia of the cervix (CIN) - to a test that examines for the presence of a currently untreatable sexually transmitted infection (HPV). This change in detection

method also constitutes a change to the social context of the screening, from a health-seeking behaviour that reduces the incidence of cervical cancer to the detection of a socially and culturally stigmatised infection which – as will be demonstrated in the literature review – may lead to increased felt or enacted stigma and the concomitant effects of stigma on identity, a ‘new type of sickness experience’ (Forss et al. 2004) and a state of liminality (Trusson et al. 2016; Blows et al. 2012; Little et al. 1998). This change will have profound implications for several reasons – the increased prevalence of HPV compared to positivity for pre-cancer or cancer of the cervix; will mean that the number of women diagnosed with HPV will increase. In addition, no treatment is currently offered for high-risk HPV positivity, in comparison to the well-established treatment regimens for cancer or pre-cancer (PDQ Adult Treatment Editorial Board 2002). Levels of support for HPV positive women have not been widely studied, and support outside of the clinical setting may be mixed due to the associated stigma. A lack of awareness or social support in turn has attendant implications for and effects on women’s social identities – including a reduction in self-esteem and self-worth (Crocker 1999), fears of disclosure and social exclusion (Wilson et al, 2014), and adverse effects on [personal relationships](#) (Newton & McCabe 2008a). In the case of persistent infection these factors also constitute a real risk for a state of liminality and biographical disruption.

#### **1.4. Comparative Prevalence of Human Papillomavirus and CIN**

The lifetime risk of contracting HPV exceeds 50% (Barr & Tamms 2007). An older study by Syrjänen et al. (1990) indicated that the risk of developing HPV for a female between the ages of 20 and 79 years was 79%. Woodman et al. (2007) found that in a sample of 2011 women (aged between 15-19, who had recently become sexually active) 1075 women who were HPV and cytologically negative at recruitment had a cumulative risk of infection at 3 year

follow-up was 44% (for any HPV type), and that incidence rates for infection with a separate HPV strain at 3 year follow-up was a further 26%. In comparison, Peto et al. (2004) studied a cohort of 13,000 women, finding that the highest prevalence of CIN1 was 6% (in women aged 30-34 years), and that the prevalence of CIN2 or CIN3 peaked at 1.0 and 1.1% respectively in women aged 35-39 years. When the factors of prevalence and lifetime risk are combined with the time interval between testing positive for any strain of HPV and developing microscopically detectable pre-malignant changes to the cervical epithelium, which studies estimate to be between two years (Moscicki, 2005) and five years (Schlecht, 2003), it is reasonable to predict that more women will test positive for HPV than the screening programme currently diagnoses with either pre-malignant disease of the cervix, or invasive cancer of the cervix.

### **1.5. *Lack of Treatment or Cure for Persistent HR-HPV Infection***

At present, there is no effective cure for a high risk HPV infection (Kling, 1992). Cervical intraepithelial neoplasia (CIN) and cervical cancer (the clinical endpoint of persistent high-risk HPV infection) may be treated by surgical excision of the affected area – known as a Long Loop Excision of Transformation Zone (LLETZ) procedure (Gunasekera et al. 1990), by cryocautery (Kaufman & Irwin 1978) or by laser ablation (Alvarez et al. 1994) or in more advanced cases by cervical amputation (trachelectomy), partial or total hysterectomy (NHSCSP 2016; Pomel et al. 2003; Landoni et al. 2001; Piver et al. 1974). Genital warts – the clinical endpoint of low-risk HPV infection are, similarly, treatable (Kling, 1992). Treatment is, generally, well-tolerated by women, although these procedures do represent significant long-term reproductive health sequelae (Ang et al. 2011) and short-to-medium term psychosocial sequelae (Sharp et al. 2011). However, ablation, surgical excision or hysterectomy for HPV infection alone – which may or may not regress without intervention (Evander et al. 1995; Ho et al. 1995) represents

over-treatment that incurs significant health and reproductive sequelae for women, and an overuse of clinical resources. Thus, at present, no curative procedure is routinely offered to women diagnosed with HPV. This is contentious as the original Wilson and Jungner (1968) recommendations for a disease screening programme state that an acceptable treatment should be offered for the disease entity for which the population is being screened; although these recommendations have since been revised in the light of population screening for genetic conditions (Andermann 2008). In addition, research by McRae et al., has demonstrated that the screening population has also voiced this concern (McRae et al. 2014)

#### **1.6. Support Outside of the Clinical Setting**

Clinical support for cancer sufferers, including cervical cancer sufferers, is well established and organised – both in primary and secondary care (NICE 2016). However, social support for cervical cancer patients and women undergoing treatment for CIN, outside of the clinical setting, is less well organised – relying on friends, family and peers (Hoey et al. 2008), although stigma associated with cervical cancer may reduce social support or perceptions of social support among non-peers (Gregg, 2011). Far fewer resources exist to deal solely with the support needs of women with HPV infection (Harvey-Knowles et al. 2012; Nack 2002; 2000). Information and advice is given in the clinical setting but reports of support amongst patients vary, with some patients reporting enacted stigma from healthcare providers during the diagnostic interview (Kosenko et al. 2012). Additionally, support may be given through provision by private providers in the form of charitable bodies such as MacMillan Cancer Support, The Eve Appeal and Jo’s Cervical Cancer Trust; but the emotional support, reassurance and reinforcement amongst friends and loved ones may be less forthcoming, due

to the sexual nature of transmission, and the possibility of stigmatization that may result from disclosing disease status (Marhefka et al. 2012; Newton & McCabe 2005; Perrin et al. 2006).

### **1.7. Social Identity and Biographical Disruption**

Despite the apparent transient nature of HPV (Evander et al. 1995) once diagnosed affected women may not be aware that they have cleared the virus until they test negative (which may not be until sometime after clearance), and women with persistent infection may report HPV positivity for several years in the absence of CIN (Stensen et al. 2016). Extended periods of uncertainty over HPV positivity, along with fears of developing cancer, of cancer recurrence and the effects of transmission to loved ones may lead to extended periods of anxiety (Kosenko et al. 2012) In addition, the fear of the consequences of disclosure – anticipated or enacted stigmas such as social exclusion, stereotyping and discrimination may have deleterious effects on identity and self-esteem, and negative psychological sequelae (Piñeros et al. 2013; Pirotta et al. 2009; Waller et al. 2007). Lastly, the liminal nature of a “new type of illness experience where neither health nor disease is confirmed or excluded” (Forss et al. 2004; Little et al. 1998; Rajaram et al. 1997; Murphy et al. 1988) all serve to indicate that HPV positivity can serve as a disruption to biography.

### **1.8. Aetiology of Cervical Cancer**

HPV is neither the first nor the only oncogenic virus endemic in the human population – other examples are members of the *Herpesviridae* family such as Epstein-Barr virus (Young & Murray 2003) and hepatitis-B virus (Kremsdorf et al. 2006). Research on the lifecycle of

papillomaviruses has been ongoing since the early 1990s and is thus well established and understood. Human papillomaviruses are members of the *Papillomaviridae* family of which, currently, over 180 types have been classified (Bernard et al. 2010; de Villiers et al. 2004). Viral particles are long, circular DNA molecules, approximately 8000 base-pairs in length and are composed of eight (currently known) genes: E1-2, E4-7 and L1 and 2. In the relative chronology of genome activation, 'E' and 'L' denote 'early' and 'late' genes respectively (Castellsagué 2008). Of the strains identified, approximately 40 can infect the genital tract (Srivastava et al. 2001; Tieben et al. 1993; Schneider & Koutsky 1992).

Genital infection with HPV occurs during intimate or sexual contact, but is not confined to transmission through penetrative sex – skin-to-skin contact is sufficient to allow infection – and thus barrier contraceptives such as condoms are of limited efficacy (Waller et al. 2003; Manhart & Koutsky 2002). The epithelium of the genital mucosa is a non-keratinising, stratified squamous epithelium. The multilayered nature of the tissue structure is the reason for one of its main functions: protection. HPV infection in superficial layers of epithelia is not considered to be an oncogenic risk, as the host cell genome is stable at this stage of differentiation (Hildesheim & Wang 2002). The risk of oncogenic potential is heightened when the virus penetrates to the basal layers of the epithelium. This is thought to occur via microscopic traumas, which may be sustained during intercourse (Muñoz et al. 2006). At the basal layer, the host cell genome is still undergoing transcription and modification and (relative to later stages of growth) is far more active (Fehrmann & Laimins 2003). HPV virions dock with and infect basal layer cells. The L1 protein (as encoded by the L1 gene) is thought to play a role in the initial attachment and docking on the cell surface (Joyce et al. 1999). Once the virus has entered the cell, the E6 and E7 genes are the first proteins to be expressed in the replication process – these two proteins increase the rate at which host DNA is synthesized by reactivating



DNA replicating mechanisms (Cheng et al. 1995). It is this activation that gives the virus its oncogenic potential, and the subsequent deregulation of host cell DNA replication that causes malignant transformation within the cell (Werness et al. 1990; Phelps et al. 1988). As the infected cells continue to grow and differentiate, HPV genes E4 and E5 are activated, resulting in the production and assembly of 'progeny' virions.

HPV subtypes can be divided into two classes – low-risk HPV types which manifest as *condyloma accuminata* or genital warts; these subtypes do not present a significant clinical risk for cervical cancer (de Sanjosé et al. 2007; Clifford et al. 2006; Stubenrauch & Laimins 1999); and high-risk HPV subtypes (Walboomers et al. 1999) associated with increased risk for cervical cancer. As previously stated, the lifetime risk of contracting HPV varies – with some authorities giving a relative risk of 50% (Barr & Tamms 2007) and others estimating between 60% (Baseman & Koutsky 2005) to above 80% (Chesson et al. 2014). The majority of individuals will naturally clear an HPV infection within two years (Trottier & Franco 2006; Franco et al. 1999), but repeated infections or infection in individuals who are immunosuppressed or who indulge in other risk factors such as smoking (Castellsague et al. 2002) may lead to a state of persistent infection which may progress to cancer (Hildesheim et al. 1994).

### **1.9. Prevalence of HPV**

As previously stated, estimates of the relative lifetime risks of contracting HPV vary from 50 to 80% (Barr & Tamms 2007; Baseman & Koutsky 2005; Syrjänen & Syrjänen 1990). According to Fenton et al. (2001) HPV is the most common sexually transmitted infection encountered in the UK, specifically HPV-6, which presents as genital warts. Of the high-risk sub-types HPV-16 is the most commonly reported variant, with HPV-16 DNA being detected in

some 40% of cervical cancers, and HPV-18 DNA being detected in approximately 30% of cervical cancers (Kitchener et al. 2006; de Sanjosé et al. 2007).

### **1.10. *Origins of the Screening Programme***

Cervical screening was introduced in the United Kingdom in 1964 (Albrow et al. 2012). However, at the time, screening invitations were sporadic and opportunistic. The current call-recall system did not exist which meant it was difficult to manage women effectively following a positive diagnosis. In addition, at the time little was known about the aetiology of the disease. Initially, it was thought that socio-economic status played a part since efficacy trials on small closed populations (such as female prisoners) had indicated that cervical cancer was more common in those of a lower socio-economic status, and to explore this, a woman was asked to indicate her husband's occupation on the screening request form. The first suspicion of HPV as an aetiology was posited in 1975 by Harald zur Hausen. The question was resolved in 1999 when the study by Walboomers et al. determined HPV as a "necessary cause of cervical cancer" (Walboomers et al. 1999).

Currently, a screening test for cervical cancer involves the exfoliation of cells from the surface of the cervix (NHSCSP 2013) These cells are preserved in a vial of alcohol and a slide is then prepared from the preserved cells, stained and examined by microscopy to identify any changes in the appearance of the nuclei of the cells (cytomorphology). Abnormal changes in the nuclei (known as dyskaryosis) indicate the presence of neoplastic disease. The degree of the abnormality is currently graded from borderline to mild dyskaryosis (low grade disease) and moderate to severe dyskaryosis (high grade disease) (NHSCSP 2013). The more severe the degree of abnormality, the greater is the likelihood that disease will progress from pre-cancer

(pre-malignancy) to cancer (malignancy). The grade of abnormality has shown a high degree of correlation with the advancement of the disease through tissue (histology) (Abulafia et al. 2003). At present, the National Health Service Cervical [NHSCSP] recommends that women are screened every three years (25-49 years) or every five years (50-65 years) (NHSCSP 2013).

### **1.11. HPV Vaccination**

In 2008, the four UK governments and the Department of Health implemented a vaccination programme with the Cervarix<sup>®</sup> vaccine manufactured by GlaxoSmithKline on the advice of the Joint Committee on Vaccination and Immunisation (Department of Health 2009). Cervarix<sup>®</sup> was directed against HPV -16 and -18, the two viral subtypes responsible for up to 70% of all HPV-related cervical cancers (Muñoz et al. 2006). The vaccine was administered to girls aged 12-13 years, with a 'catch-up' programme running concurrently in the same year for older girls, with a view to immunising all girls aged 12-18 years in 2008, and focusing on 12-13 year girls thereafter. In 2012, the Department of Health changed its vaccination policy, opting to administer Gardasil<sup>®</sup> vaccine, a quadrivalent vaccine effective against HPV-6 and -11 (responsible for the development of genital warts) in addition to the high risk subtypes -16 and -18. Although both males and females may contract and transmit the virus, and both sexes may develop HPV-related cancers; currently only females are vaccinated against HPV. Since the implementation of the HPV vaccination programme, there have been calls for vaccination in males, in order to offer them the same health protection benefits (Chesson et al. 2011; Reiter et al. 2011; Kim et al. 2007), and research is currently being undertaken to model the cost-effectiveness, acceptance and uptake of the vaccine in males (Stanley, 2014). The case for

vaccination in males is advancing, with Public Health England announcing a scheme for vaccinating men who have sex with men (MSM) (PHE 2016a) in May 2018.

The vaccine has met with some controversy among faith schools, parents and religious groups both in the UK and in North America (Haber et al. 2007; Larkin 2007). Objections raised in the media covered the possibilities and consequences of physical side-effects (Reiter et al. 2009), the need for booster vaccinations, the possibility of sexual disinhibition in young girls (Brewer et al. 2007) and the perception of vaccinated girls by society (Casper & Carpenter 2008). Objections to vaccine acceptability among parental groups were associated with ethnic differences, with 'religious reasons' often cited in declining the vaccine (Marlow et al. 2009). Nonetheless, the majority of healthcare professionals welcomed the advent of the vaccine – hoping that it would reduce the incidence of disease (Goldie et al. 2004). Data from Scotland indicate that this is indeed the case with Pollock et al. (2014) reporting a reduction in both low and high-grade cervical lesions in vaccinated women in the Scottish Cervical Screening Programme (SCSP). Scotland is used as a data source here as women in Scotland are invited for their first screen at age 20, and the cohort of women vaccinated as girls at ages 12-13 years have already entered the screening programme, whereas women vaccinated at age 12 in 2008 in England will not enter the NHS Cervical Screening Programme until 2020-2021. Studies published in Australia also indicate that the incidence of genital warts is also reducing as a result of vaccination (Ali et al. 2013; Read et al. 2011).

### ***1.12. HR-HPV Triage and Test of Cure Algorithms***

The current programme algorithms for high-risk HPV triage and test of cure are shown overleaf. This version of the algorithm was implemented in 2012 in order to manage women showing a borderline or low-grade abnormality (triage); women who demonstrate CIN1 on biopsy which has been left untreated (conservative management) and women who demonstrate persistent high-risk HPV positivity post conisation. The aims of this algorithm are to reduce the number of women needlessly referred to Colposcopy with a high-risk HPV-negative borderline or low-grade abnormality (which poses a risk of over-treatment); and to reduce the number of women on ten years' annual cytology surveillance following treatment for a high-grade abnormality. The algorithm charts are shown here to help identify populations of women who are high-risk HPV positive but either do not demonstrate CIN and are not treated (and for whom HPV-infected cervical tissue is therefore not excised) or who remain HPV positive after treatment.



### NHS Cervical Screening Programme Screening Protocol Algorithm for HPV Triage and TOC

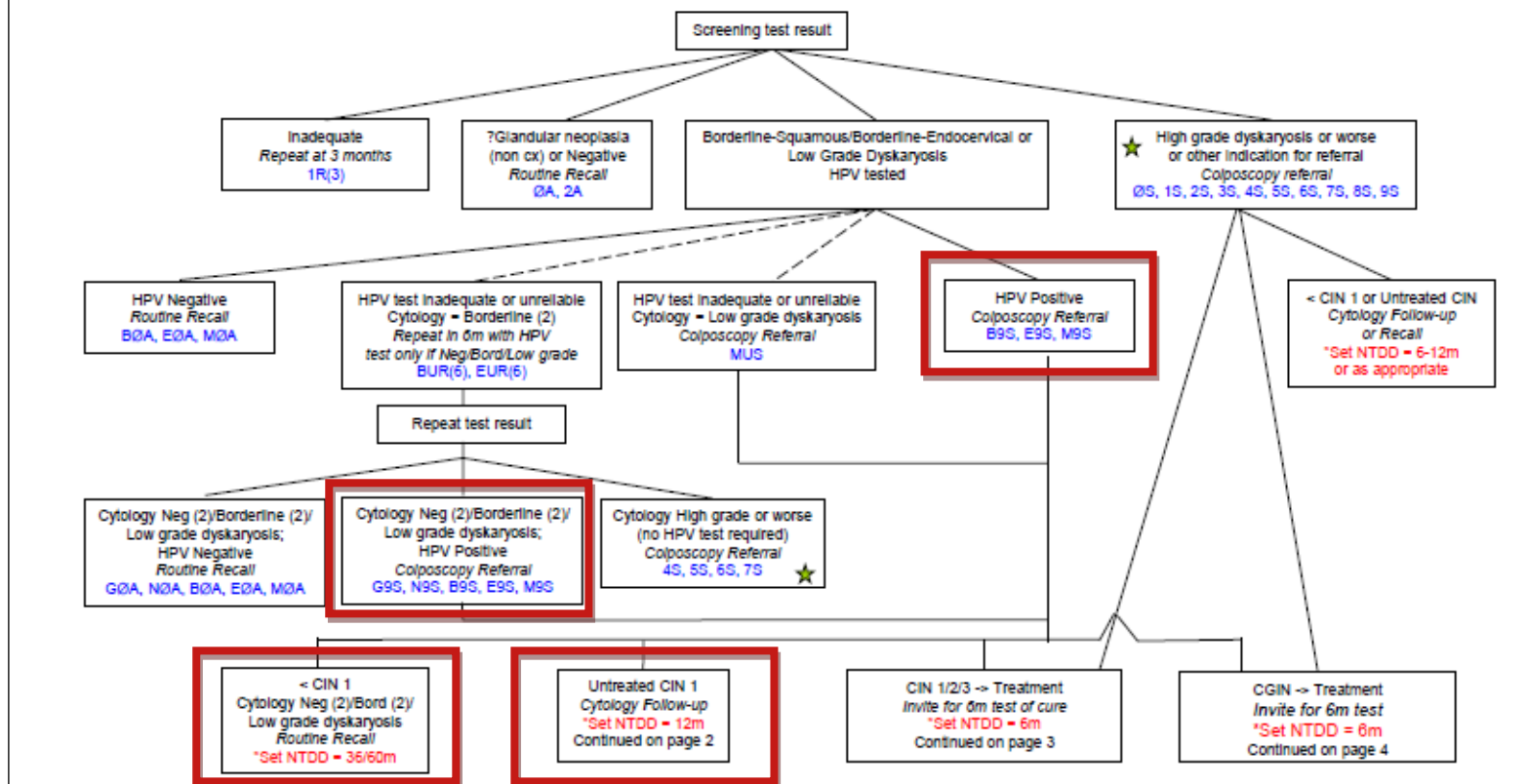
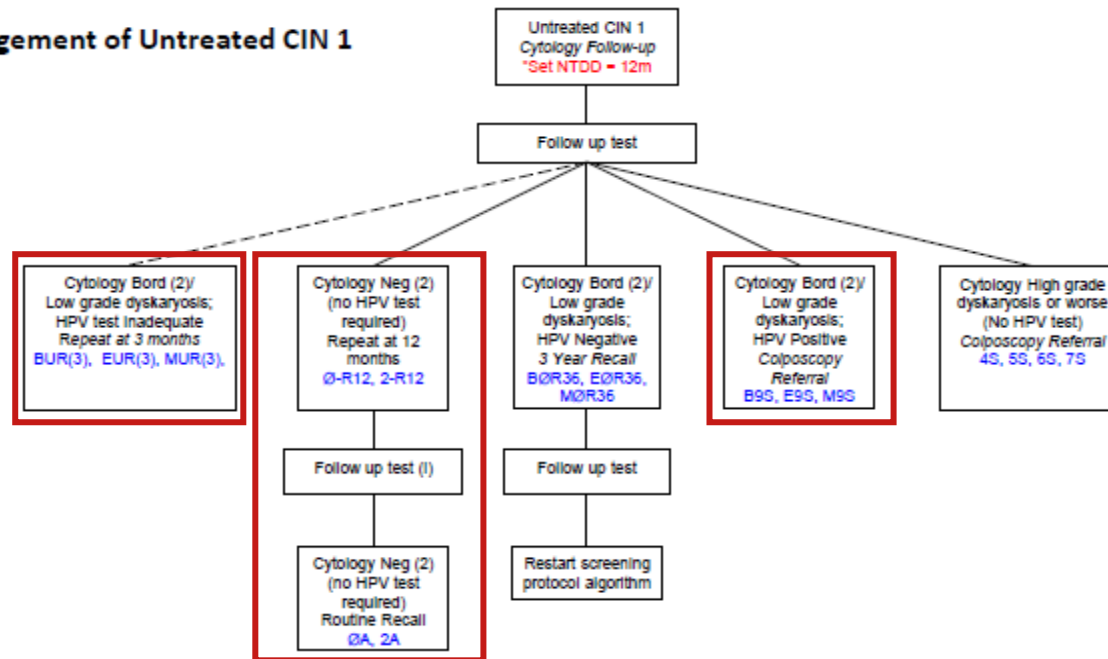


Figure 1.1: Screening Protocol Algorithm for HR-HPV Triage and Test-of-Cure from April 2014



### Management of Untreated CIN 1



(i) The management of women with abnormal cytology at this second 12 month follow up test will mirror that at the first 12 month repeat test.

Figure 1.2: Protocol Algorithm for Management of Untreated CIN 1

As is demonstrated in the screening protocols in figures 1.1 and 1.2, there are a number of women who will be diagnosed with a low-grade abnormality and sent for HR-HPV triage. In the case of HPV-negativity, the woman remains under the care of her GP or other health professional and may expect to be called for cervical screening in either 36 or 60 months (dependent on age). In the case of HR-HPV positivity, the patient is referred to Colposcopy for further examination (NHSCSP 2016). Colposcopy is a process of macroscopic examination of the cervix and vagina using a colposcope by a Consultant Gynaecologist or by an appropriately qualified Nurse Colposcopist. At Colposcopy, dependent on the outcome of a visual examination of the cervix via the colposcope, the clinician may decide:

- To arrange treatment of the patient
- To biopsy suspected areas of abnormality
- Not to treat the patient by excision of any suspected areas of abnormality but arrange for a follow-up examination in 6 months.

Thus, in the case of women for whom possible CIN1 remains untreated (at the clinician's discretion), or who are HPV-positive post treatment, or who have low-grade dyskaryosis that has not been re-tested to confirm HPV-negativity; there is the real possibility that these women will be carrying the sociological and psychological stigma of positivity for an STI and the fear of progression to or recurrence of a cervical malignancy. Women who might possibly fall into these categories are marked in red on figures 1.1 and 1.2. These women will have had some reassurance in clinic, but may need further information or support outside of the clinical setting.



### HPV Primary Screening Pilot Protocol Algorithm

All women aged 25-64 on routine call/recall and early recall

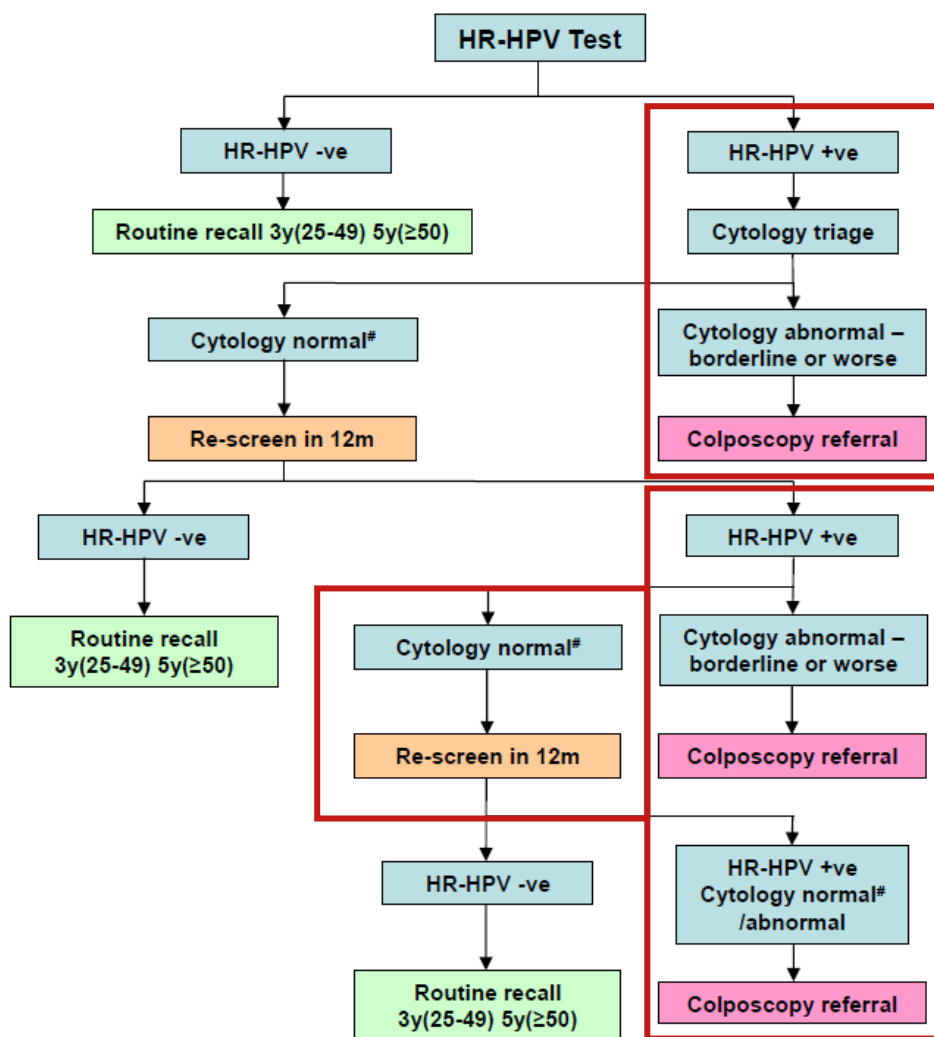


Figure 1.3: HPV Primary Screening Pilot Protocol Algorithm identifying HPV positive, cytology normal women

In the future, once HPV primary screening is implemented, women who test positive for HPV but demonstrate no nuclear abnormalities on cytology (marked in red on figure 1.3) will be at risk of the sociological and psychological sequelae of HPV positivity and anxieties surrounding progression or recurrence, without the reassurance or resolution that excisional or destructive treatment of CIN might bring.

### **1.13. Public Awareness of Cervical Screening**

Cervical cancer and the cervical screening programme have received increased public attention in recent years. In 2004, the National Health Service Screening Programme raised the entry age to the cervical screening programme ('first call') from 20 to 25 years (Sasieni et al. 2010). Although studies have found that this change is unrelated to an increase in cervical cancer incidence in women between the ages of 20-29 years (Patel et al. 2012), affected individuals and patient groups have become increasingly vocal in their petitions to get the entry age returned to 20 years (Albrow et al. 2012). Inevitably, in the years following the increase in age at first screen, tragic cases of women who were diagnosed with inoperable cancers prior to the age of screening commencement or at their first screen have received coverage in the newsprint media (Bell & Seale 2011). In the years following the change to the screening age, advertising/uptake campaigns released prior to and during the implementation of the HPV vaccine have increased public awareness since 2007 (Dodd et al. 2014; Bowyer et al. 2013; Marlow et al. 2013; Klug et al. 2008; Marlow et al. 2007). Following the introduction of the vaccine campaign, the newsprint media frequently featured stories of adverse reactions to the vaccine (Habel et al. 2009; Hilton et al. 2010), provoking further controversy and debate. Less than a year after vaccine implementation, media coverage of the death of reality TV personality Jade Goody of cervical cancer ensured that cervical cancer stayed in the public consciousness (Hilton & Hunt 2010; Hilton et al. 2010). Thus the cervical screening programme and the implementation of HPV vaccination have courted much discourse surrounding the politics of embodiment and ownership (Casper & Carpenter 2008); and the dichotomy of vaccinating pre-pubertal/pubertal girls against a potentially oncogenic, STI versus vaccinating to encourage sexual disinhibition through misunderstood notions of complete protection against STIs (Brewer et al. 2007; Haber et al. 2007). It is against the

backdrop of these developments that the introduction of HPV triage and test-of-cure in 2012 took place, and against which the roll out of HPV primary screening by 2019-2020 is proposed (PHE 2016b).

The degree of argument in both clinical and public domains surrounding the screening age and HPV vaccination give some indication of the stigma and debate that awaits women who actually test HPV positive. This research project intends to examine women's views on the use of HPV-related online resources to manage their questions, information needs and to document the lived experiences of women who are HPV-positive.

#### ***1.14. Research Project Overview***

It is thus within the complicated and changing social and cultural contexts and values surrounding screening, awareness campaigns for and media coverage of HPV vaccination, the stigmatised nature of STIs and the state of liminality invoked by screening and persistent HPV infection, that this research project is situated. This research is specifically intended to examine the lived experiences of women who have high-risk HPV (with or without accompanying cervical neoplasia) with a focus on the use of online resources in the physical and sociological self-management of persistent infection with a stigmatised virus. This research aims to document the ways in which women view persistent HPV infection and their interactions with online resources and support and to examine how both HPV positivity and online support have impacted on their lives.

This chapter reviewed the current literature on the human papillomavirus from a biomedical perspective – examining the aetiology of cervical cancer and the current and

future proposals for the screening programme and identifying the instances of persistent HPV infection within these programmes where women are not routinely offered treatment and are thus at risk of liminality and biographical disruption.

Chapter 2 will examine the self-concept, stigma theory and the sociological effects of stigmatised disease, both from an individual and a societal perspective, and demonstrate how these effects when combined with uncertainty and liminality, persistent HPV positivity may constitute a biographical disruption similar to the descriptions of chronic illness as a disruption to biography as described by Bury (1982). Strategies to mitigate both stigma and biographical disruption will then be explored, including peer support and the specific role that online support plays within this sphere.

Chapter 3 will examine the methodology and philosophical underpinnings of the study, including the overarching ontology, epistemology, theoretical assumptions and research philosophy. This will include an examination of the phenomenology of illness, a critique of phenomenological research in healthcare, the advantages and disadvantages of mixed methods research and a discussion of qualitative data gathering techniques such as interviews.

Chapter 4 will describe the collection and analysis of the quantitative, questionnaire data. This data will be used to describe the characteristics of a population of individuals using a social media based support group and online resources in the management of HPV positivity drawing on the issues identified in the literature review. Demographic aspects of a social media based population will be discussed, along with information surrounding disease stage and screening history. Internet use and behaviour will be examined and reported.

Chapter 5 will examine the qualitative data obtained from online interviews/narratives. The demographics of the participants and summaries of their stories will be reported. The super-ordinate and sub-themes that became apparent in their responses will be demonstrated and discussed. As the study was exploratory in nature, and mixed-methods by design equal weighting will be given to the results from each method and analysis.

Finally, Chapter 6 will present a detailed synthesis and discussion of the key findings, focusing on areas for action, practice improvement, applications and recommendations to public health. The limitations of the study, the claims of contributions to knowledge, suggestions for further study and the application of the findings to the researcher's professional practice will also be described in this section.

## **Chapter Two – Literature Review**

### **2.1. Introduction**

The first chapter examined HPV positivity from a biomedical standpoint and focused on the aetiology of the disease and its clinical endpoints – namely the incidence and prevalence of HPV, the development of CIN and cervical cancer and the use of HPV DNA in cervical disease detection, management and prevention through a vaccination programme. However, to focus only on these aspects of the human papillomavirus is to neglect an entire field of research surrounding the invisible effects of HPV positivity – namely the psychological effects on the self (Daley et al. 2010; East et al. 2010; McCaffery et al. 2010) and the sociological effects on identity (Charles 2014; Boyd 2010; Nack 2002, 2000). A review of the qualitative literature on STIs in general, and HPV in particular, shows stigma to be a common theme reported among affected individuals (Kim 2012; McCaffery et al. 2006; Perrin et al. 2006). As the concept of stigma is intricately associated with both the self in terms of perceptions of self-worth and self-esteem; and with identity in terms of identity negotiation and role-behaviour, many of the psychological sequelae of HPV-positivity are bound up with and emanate from the social consequences of disclosure. For example, the disclosure of positivity for a sexually transmitted disease may result in social rejection or exclusion – affecting identity and perceived role fulfilment. These effects on identity may, in turn, lead to negative psychological sequelae such as anxiety and depression. The literature review will therefore encompass theories of the self-concept and identity, in addition to the theory of stigma. In addition, stigma management and communication (Heijnders & Van Der Meij 2006) and the notion of stigma as a gendered social construct (Brankovic et al. 2013) will be discussed. The concept of disease as a biographical disruption (Bury, 1982) will also be

examined along with the concepts of social and peer support and the role that online support plays in this arena (Wright 2016; Rains et al. 2015; Hong et al. 2012; Eysenbach et al. 2004b; Klemm et al. 2003).

## **2.2. Self and Identity**

Whilst 'self-concept', 'self' and 'identity' are used interchangeably throughout the literature examined in this section, and it is important to make distinctions between them, as the different meanings they possess are important within the context of both the literature and the wider research project. The self-concept is largely associated with the field of symbolic interactionism (Elliott 2013, p.30) and the writings of George Herbert Mead. Mead was a founding figure in the field of pragmatist philosophy and a major figure in the development of the American School of philosophy (Cronk 2017). Apart from his work on the self, Mead (along with Charles Horton Cooley) is most regarded for his work in founding the field of symbolic interactionism – a sociological perspective that postulates that individuals act toward objects based on the meaning that those object have for them (Mead et al. 2015, p.136). However, whilst the theoretical lens through which this research is viewed is interpretivist rather than symbolic interactionist, the two fields are closely allied and aligned and sit under the same paradigmatic umbrella of constructionism. Moreover, both fields are amenable to phenomenological study. In addition, the definitions of self advanced by Mead *et al* (2015) are the best fit, philosophically, with the other constructions advanced in this chapter (such as stigma and social support) and thus will be used here, despite the research being interpretivist in nature.

The development of the self-concept in sociology can be traced back to Cooley (Gecas 1982; Epstein 1973), who, expanding on the work of psychologist and philosopher William James' 1890 treatise on the principles of psychology, described the concept of the 'looking glass self'. Epstein recapitulates several models of the self as described by sociologists in the first part of the nineteenth century, including Cooley who in 1902 first described the possibility of alternative modes of self-perception (Shaffer, 2005). The looking glass self has three components:

*'First, actors learn about themselves in every situation by exercising their imagination to reflect on their social performance. In doing so, they imagine themselves as others must see them, and this construction of what others must see is fundamentally like an image reflected back in a mirror. Secondly, Cooley argued that actors next imagine what those others must think of them. In other words, actors imagine the others' evaluations of the actor's performance. Third, and most important, the actor experiences an affective reaction to the imagined evaluation of the other.'*

Shaffer (2005)

Cooley's writings were contemporaneous to and often critiqued by Mead. In his posthumous work *Mind, Self & Society*, Mead abandons the concept of 'a substantive soul endowed at birth' (Mead et al. 2015, p.22) and holds that the individual develops the idea of self and self-consciousness from experience. In describing his definition of social psychology, Mead states '...minds and selves are essentially social products, products or phenomena of the social side of human experience'. Mead therefore viewed the self as a social construct and the development of the self as a social process, and this notion was fundamental to his later writings on and espousal of symbolic interactionism as a sociological philosophy. Inghilleri puts forward the notion that Mead expanded on Cooley's writings, describing the self as having two main aspects: the 'I' and the 'me'. The 'me' is the concept of self as learned through interaction with others. According to Inghilleri:



*'...other people's attitudes as specific or generalised as they may be, once internalised in the self, will constitute the 'Me'. The 'Me' is that part of the self that can be observed as an object and that can be described as a subject.' In tandem with the concept of the 'me' arises the entity that is the 'I'. The 'I' reacts to the self that which arises through the taking of the attitude of others.'*

(Inghilleri 1999, p.26)

Additionally, the 'I' is:

*'...the principle of action and of impulse; and in its action changes the social structure... [T]he individual is no thrall of society. He constitutes society as genuinely as society constitutes the individual.'*

(Mead et al. 2015, p.xxv)

Both Cooley and Mead posit that our conception of the self is constructed through interaction with others. Stryker and Burke – prominent authors in the field of identity theory, claiming Mead as their intellectual heritage – agree that his framework (albeit highly simplified for the purposes of their writing) asserts that 'society shapes self, shapes behaviour' (Stryker & Burke 2013). Stryker and Burke expand on the socially constructed Meadian self, stating that individuals inhabit, enact and negotiate multiple roles in multiple groups.

### 2.2.1. Identity – The Content of Self-Concepts

Consequently, if as argued above, interaction with and observation of society shapes the self, the question of locating identity in the self-concept framework arises. According to Tajfel, sociology refers to identity as our ability to locate ourselves in a social world. This locating occurs through the negotiation and membership of various groups such as family,

friendship groups, gender groups, race groups, school or educational institutions, occupations, religious groups, sports teams and political affiliations (Tajfel 2010, p.122). He also goes on to describe social identity as 'that part of an individual's self-concept which derives from his knowledge of his membership in a social group (or groups) together with the value and emotional significance attached to that membership'. In his review of the self-concept, Gecas (1982) posits that identity is constructed within the self, and is 'situated, emergent, reciprocal and negotiated'. Luhtanen & Crocker (1992) define personal identity as how individuals view themselves, whereas social identity refers to how an individual views the social groups to which he or she belongs. Writing of the effect of chronic illness on identity, Nettleton defines the difference as follows: 'chronic illness can impact upon sufferers' daily living, their social relationships, their identity (the view that others hold of them) and their sense of self (their private view of themselves)' (Nettleton 2006, p.72). Thus a number of scholars have argued that identity emerges through the negotiation and habitation of roles within chosen social groups (Stets & Burke 2000; Swann 1987).

### *2.2.2. Threats to Identity*

The previous section established an argument for the self-concept as created via interaction with and feedback from society; and the construction of identities within that self being achieved through the negotiation and habitation of social roles and membership of social groups. How then, does an individual react when his or her membership of a chosen group is jeopardised? Social membership may be threatened by the acquisition of a characteristic that breaches group rules, or that other group members find distasteful or socially discrediting; membership of the group is threatened, and thus that area of an

individual's identity is threatened. If the discrediting characteristic – such as illness – is disclosed to a group, social rejection may ensue (Crandall & Moriarty, 1995) – whether familial, romantic or among peers – resulting in social isolation (Fife & Wright 2000).

HPV can be interpreted as a socially discrediting characteristic as the sexual nature of transmission (Burchell et al. 2006) and lack of awareness surrounding prevalence (Dodd et al. 2014; Bowyer et al. 2013; Waller et al. 2007) imply promiscuity or infidelity among HPV positive individuals (Newton & McCabe 2005). Promiscuity and infidelity are viewed as socially deviant, particularly among women (Nack 2000) and thus the disclosure of positivity for an STI implies deviance from social or cultural norms (Gregg 2011). Hence the examination of the self as a social construct (arising from interaction with others), and of identity (arising from role negotiation and habitation) are both important as the sociological and psychological sequelae of HPV positivity are derived from the social consequences of disclosure. Disclosure of HPV positivity can be construed through the Meadian lens as an interaction or social transaction with social groups (Hult et al. 2012). If, as argued above, the content of self – identity – is formed through the habitation of roles and membership of groups, and those memberships are threatened, identity itself must be threatened. Due to the intimate nature of transmission – HPV is only transmitted by intimate genital or sexual contact (Manhart & Koutsky 2002; Koutsky 1997) the social consequences of disease disclosure are associated with the stigma of implied deviations from social/moral norms (Scambler 2009; Scambler 2006). Stigma is, in itself, a social construct, the origin and structures of which are discussed below.

### **2.3. Stigma**

Stigma was first examined as a social concept by Émile Durkheim, who, alongside Weber and Marx, is considered one of the founding figures of sociology (Calhoun et al. 2012, p.107; Franzese 2009, p.12). Durkheim published *The Rules of the Sociological Method* in 1895, and in doing so became the first writer to apply scientific methods to sociology, and to argue that sociology be acknowledged as an academic discipline (Poggi 2000, p.2). Durkheim felt it was important to study the patterns of behaviour or social facts that are attributable to or enacted by any specific group (Berkman et al. 2000). Durkheim was also the first writer to examine the concept of stigma in depth, in his work *Le Suicide* – describing stigma as a consequence of deviation from a societal norm or set of norms (Douglas 2015, p.9).

Aside from Durkheim, writing on the concept of stigma is dominated by the work of another prominent sociologist, Erving Goffman. Since its publication in 1963, Goffman's seminal work *Stigma: Notes on the Management of a Spoiled Identity* has been a reference point for many authors of stigma research. Goffman had already expanded on the Meadian concept of self in his 1959 work *The Presentation of Self in Everyday Life*. Whereas Mead described the self as a social construct, Goffman took this idea one step further, describing the self not only as socially constructed, but created, supported (by props such as the choice of clothes, jobs and houses) acted and performed as a piece of theatre (Goffman 1990a, p.18). His later work, *Stigma*, went on to examine the coping mechanisms and consequences that arise in the event that the role(s) assumed as social identity are discredited.

### 2.3.1. *Origins of Stigma*

Both Goffman and, later, Jones (1987) cite Greco-Roman society as the origin of stigma, where it was originally utilised as a method of publicly identifying persons of ill-repute. Ritual marks or blemishes – brands, burns, scars or tattoos – indicated that the bearer was the possessor of unusual or unsavoury traits, such as membership of the slave or criminal classes. Stigmata were applied to such individuals in order that ‘normals’ might avoid them socially (Goffman, 1990b p.11). Speaking in a more modern and universal context, Falk notes ‘...we and all societies will always stigmatize some conditions and some behaviours because doing so provides for group solidarity by delineating ‘outsiders’ from ‘insiders’ (Falk 2001, p.13). Scambler (2009) reiterates this, stating ‘...it is the disgrace itself that is marked. In this way the solidarity of normals is affirmed’. Goffman described stigma as ‘an attribute that is deeply discrediting’ but opined that ‘a language of relationships, not attributes, is really needed’ (Goffman, 1990b, p.13). This example illustrates a theory delivered later in his work – that society can be divided into the stigmatised and the stigmatisers, or, as later authors describe, ‘in-groups and out-groups’ (Oyserman 2001). Goffman’s work on the stigmatising characteristics of mental health and disability as deviations from social norms (Goffman 1992, 1991) form the basis of theoretical models for understanding other, more recent stigmatised conditions such as HIV/AIDS (Judgeo & Moalusi 2014; Alonzo & Reynolds 1995) and, as will be demonstrated later in the chapter, positivity for HPV and the development of cervical cancer.

According to Campbell and Deacon’s readings of Goffman, they attribute the application of Goffman’s model of stigma to three universal and historical forms (Campbell and Deacon, 2006):

1. The possession of overt or external deformities, such as missing a limb or being confined to a wheelchair.
2. Known deviations in personal traits – such as gambling or alcoholism, or affliction with mental disorders.
3. Tribal stigma – association or affiliation with a specific nationality, religion or race.

### *2.3.2. Overt or External Deformities*

In the case of HPV, the first form of stigma – overt or external deformity – is difficult for society to apply to affected women until disclosure has been undertaken, as high-risk HPV is largely asymptomatic and also affects an intimate area that is neither visible nor spoken of in everyday life, thus positivity for high-risk HPV can be construed as an ‘invisible stigma’. However, in a quantitative study examining internalised shame, intrusive thoughts and quality of life scores between a control group of orthopaedic patients and a sample of women with external genital warts (which have a lower risk of developing into cervical cancer than non-wart causing HPV strains), Jeynes et al. (2009) found that women with genital warts showed higher levels of shame, greater frequency of intrusive thoughts and lower quality of life scores than the group with orthopaedic injuries. In addition the Jeynes study found that women report feelings of disgust and self-disgust to a diagnosis of genital warts. In short, these women felt or anticipated stigma on the basis of Goffman’s first criterion, that of the deformed physical body. Even in the case of asymptomatic HPV, a participant in a study by McCaffery *et al* (2006) who was HPV positive but cytologically normal reported ‘there’s a leper type deal to it’.

### *2.3.3. Deviations in Personal Traits*

Once the sexual nature of transmission is understood, however, Goffman's second criterion is more often, although inaccurately, applied – as a known deviation in a personal trait. In the case of HPV the assumed flaw is moral – the assumption of promiscuity or infidelity. An earlier study by McCaffery et al. (2003) conducted a series of focus groups among ethnic minority women which showed that the women felt that HPV positivity was associated with infidelity, mistrust and blame; and that participating in HPV screening implied feelings of mistrust and suspicions of infidelity to their partners and family. It should be noted that these attitudes were produced only by the question of participating in screening and the anticipation of a positive result. These women had not been invited for HPV screening at the time of the study, nor were they in expectation of HPV positive results, thus these attitudes were in response to hypothetical HPV positivity.

### *2.3.4. Tribal Stigma*

Research into HPV positivity and stigma has tended to focus on the first two criteria of Goffman's model, but studies by Nack (2008, p.80; 2002, 2000) indicate that women affected by HPV and/or herpes had, until the point of their own diagnosis, imagined a dichotomous population of 'good girls' and 'fallen women'; terms that Nack considered to indicate that perceptions of STIs were gateways to a tribal model of stigma. Both the terminology used by participants, and the responses given in interview, lead Nack to believe that HPV was also a gendered stigma, with blame being attributed to and shame being more overtly felt by women who were affected by the virus (Brankovic et al. 2013). This finding was reiterated in an ethnographic study by Gregg (2011) of Brazilian women suffering cervical

cancer. While we know that HPV is a necessary cause of cervical cancer, whether the women in Gregg's study knew of this is not made clear, but Gregg found that 'women with cervical cancer were not just considered ill, they were also assumed to be dirty, lazy and promiscuous'. Gregg also states within her paper that 'men are expected to control the sexuality of women in their families and to have complete sexual liberty themselves'.

### 2.3.5. *The Discreditable and the Discredited*

According to Goffman's classification, stigmas may be separated into 'discredited' stigmas (those that are immediately visible or known to others (e.g. skin colour or visible disability such as a missing limb or being in a wheelchair), and 'discreditable' stigmas – invisible or concealable stigmas, such as sexual minority status, HIV or mental illness. As an asymptomatic infection HPV is thus categorised as a 'discreditable' condition or an 'invisible stigma'. A discreditable individual is one whose stigmatising characteristic is not immediately visible or not yet disclosed. Discredited individuals are those whose stigmatising attribute is either patently visible or has been disclosed to non-stigmatised individuals (Chaudoir et al. 2013). This aspect of stigma is particularly important when considering the disclosure of a positive HPV diagnosis to others, which may affect access to support channels. As the stigmatising characteristic is both asymptomatic and invisible it need not be disclosed to many others in an individual's social circle, unless that individual must disclose in order to access social support, an act that may in itself risk social rejection.

As part of the discredited/discreditable dichotomy, Goffman also described two methods of stigma management – *passing* and *covering*. According to Leary (1999) passing is 'a cultural performance whereby one member of a defined social group masquerades as



another' in order to enjoy the social privileges afforded to the dominant group (Kanuha, 1999). Due to the invisible nature of the stigma, HPV positive individuals may pass as uninfected to partners, family or friends by omitting to disclose the nature of their condition. Research on HPV disclosure has determined that fear of social reprisals (rejection, exclusion, public shaming) are major reasons why women fail to disclose their condition (Keller et al. 2000). However, as the results of data collection show in later chapters, the majority of women affected by HPV indicated that they would disclose their condition to significant others.

Goffman expanded on Durkheim's theory of stigma as a consequence of deviance from a norm, describing it as a social process. Stigma as a social process echoes Mead's concept of the construction of the self as a social process. Goffman tied the concept of stigma to the notion of the self by describing stigma as a cause of spoiling an individual's social identity. This disqualification comes about as society or societies 'establish a means of categorising persons and the complement of attributes felt to be ordinary and natural for members of each of these categories' (Goffman, 1990b, p.11) – and that visible evidence of failing to meet these standards, be they physical, mental, behavioural, socioeconomic, tribal or religious will result in that individual failing to be accepted by that group, and thus stigmatised. Goffman reiterates Mead's concept of the 'I' and the 'Me' in his model of stigma, stating that society assumes demands and imputes characteristics to ourselves and categorise both ourselves and others we see as 'us'. Goffman refers to this construct of our self as 'the virtual identity' – corresponding to Mead's concept of 'I'. In contrast to this, the actual character or categories and attributes that individuals could actually be proved to possess is the actual social identity – Mead's 'Me' (Goffman 1990b, p.55). Goffman theorised that stigma arises as a discrepancy between the virtual social identity – one that we

construct subjectively to make sense of how we see others' perceptions of us – and the actual social identity – one that we form in the receipt of actual, objective feedback from others in our daily interactions.

### *2.3.6. The Own, the Normals and the Wise*

Goffman theorised that the structure of stigma relied on three specific populations: the stigmatised (the 'own'), the 'normals' and the 'wise'. Normals are individuals who are unaware of the stigmatised condition of the affected person and to whom disclosure of the stigma may represent the risk of being socially discredited. In relation to HPV positivity, normals represent the individuals to whom affected persons would not wish to disclose their HPV positive status – this may include family, friends, loved ones, employees and their wider social world. The 'wise' refers to individuals who have been apprised of the stigmatising condition but who accept the stigmatised individual as a 'normal'; with whom the stigmatised individual can interact without the anticipating stigma or shame. The wise may be seen as 'honorary members' of the stigmatised group. The wise population includes fellow sufferers, members of the close social circle who have been informed of the individual's disease status and healthcare staff, who would be expected to suspend moral judgement based on their professional knowledge of the condition. However, according to participants in a study by Nack (2002, 2000) some healthcare practitioners have exercised moral judgement during the diagnostic encounter, emphasising the stigmatising nature of the condition at the point of diagnosis. Originally purely theoretical, the 'own and the wise' model of different populations within a sphere of stigma was recently demonstrated by Smith (2012), and within this research study was the author's experience in the acceptance

to the groups from which participants were recruited – once gatekeepers had accepted the researcher’s professional credentials, the researcher was accepted as one of the ‘wise’ within participant populations.

### 2.3.7. *Other Models of Stigma*

Goffman’s model has been the dominant theory in the field since it was published. However, more recently authors have sought to expand on the traditional model. Jones et al. (1984) describe a further model of stigma based on Goffman’s two conditions: the discreditable and the discredited. On the basis of these groups and the management techniques of passing and covering, Jones’ team proposed six dimensions of stigma, by which the level of social censure might be determined. These six dimensions are as follows:

1. Concealability – extent to which the condition is concealable from others – invisible conditions will evince less stigma than highly visible ones.
2. The course of the mark – whether the stigma’s prominence increases, decreases, or remains consistent over time. Examples might be leprosy, or Kaposi’s sarcoma; the more overt or spreading the ‘mark’, the greater the stigma.
3. Disruptiveness – the degree to which the stigma and/or others’ reactions to it impede social interactions. Epileptic *grand mal* seizures, acute schizophrenic/manic episodes or autistic ‘meltdowns’ in public (Ryan, 2010) are examples of stigmatised attributes that are more stigmatised based on the amount of attention they draw – the more attention, the more stigma.

4. Aesthetics – the subset of others' reactions to the stigma comprising reactions that are positive/approving or negative/disapproving but represent estimations of qualities other than the stigmatized person's inherent worth or dignity
5. Origin – The origin of the stigma – whether present at birth, the result of accident or the result of deliberate behaviour will affect the degree to which it is stigmatised.
6. Peril – The threat that 'normals' perceive the danger might pose to them – whether accurately or otherwise.

Taken from Jones (1984) In: (Heatherton 2003, p.6))

Although developed in relation to mental health stigma, later writings by Corrigan (2006, 2001, 2000) added the dimensions of stability, controllability and pity to existing models of stigma. According to Scambler (2009), Goffman's model is still relevant, but researchers need to go beyond this original model as it doesn't necessarily reflect aspects of modern life. In their paper reconceptualising stigma, Link & Phelan note that the definition of stigma has varied widely, principally due to the application of the concept to a wide range of subjects and the multidisciplinary nature of the research (Link et al. 2001). They raise two challenges to literature framed by Goffman's concept; firstly that the majority of researchers do not belong to stigmatised groups, and secondly that research on stigma has a largely individualistic focus. The first challenge definitely bears relevance for this researcher – as an HPV-negative individual, the researcher carried the label of 'normal' which made it difficult to establish rapport with some groups that fitted the sample population. Nack (2002, 2000) reports that her own status as a fellow sufferer was helpful in her research surrounding HPV stigma. Within this piece of research, the position that the researcher occupied within the group was as 'one of the wise' due to the nature of her profession, but the absence of the

stigmatising condition was still a barrier to some individuals. This is discussed further in the qualitative data gathering and analysis section. Link & Phelan's second criticism – that stigma research has a largely individualistic focus is also undeniable.

### *2.3.8. HPV as a Source of Social Stigma*

The stigma concept has been applied to many disciplines within the field of healthcare research, including cancer (Fife & Wright 2000; Koller et al. 1996) and mental illness (Corrigan 2006); however in recent years, research on health related stigma has focused on sexually transmitted diseases [STDs], particularly HIV/AIDS (Flowers et al. 2006; Visser et al. 2006; Bunting 1996). However, there is a paucity of sociological research into the social stigma attached to a diagnosis of HPV – research into the psychological sequelae of HPV positivity is more plentiful, and will be discussed in the next section. Entering the search terms 'HPV', 'stigma' and including the words 'knowledge' and 'attitudes' and into various databases including Google Scholar produces some 8,300 article results. The same search run through Medline, CINAHL and the Cochrane Database produces remarkably fewer results – 63 in all – although this may be due to the fact Medline largely deals with quantitative/positivist studies and the article titles of qualitative studies tend to have rather more descriptive and abstract titles that do not always include the search terms initially entered (Evans 2002). However, the majority of these papers examine knowledge and attitudes of HPV vaccination as opposed to HPV positivity, and those that examine stigma examine the effects of stigma on psychology. When this search is refined to include the terms 'social stigma' or 'sociology' or 'sociological' and to exclude the terms 'vaccine', 'vaccination', 'psychology' and 'psychological stigma', a total of five studies were returned. Aside from Nack's two studies surrounding the social aspects of HPV stigma (2002, 2000),

East et al.'s 2010 paper on the stigma of sexually transmitted infections and Gregg's (2011) study of the social stigma associated with cervical cancer; one study reviews the stigma of sexually transmitted infections, including HPV, although it is not the main focus of the research (Hood et al. 2011). Where research does examine social stigma among women it studies perceived, anticipated stigma or enacted stigma. Enacted stigma 'is when people who are considered to be morally, socially, racially, or physically tainted are actively discriminated against by so-called 'normals': felt stigma is the fear or experience of this type of discrimination' (Lichtenstein et al. 2005: 44). Participants in Nack's 2002 study – examining chronic STD diagnoses (including HPV) report (perceived) enacted stigma by health professionals:

*'Practitioners also expressed negative feelings verbally about the women to whom they delivered news of a serious shift in health status. Louise, a twenty-eight year-old white middle-class graduate student, received a harsh HPV diagnosis over the telephone. 'He was very accusatory, like now I was this big pain in the ass for having a bad pap smear... I got him on the phone, and he's like: 'You have cancerous growth all over your cervix. It's everywhere. It's probably HPV. You probably picked it up from some guy''. Not only had her doctor described a very significant part of her body as ravaged by cancer, but he had also marked her as promiscuous.'*

(Nack 2002)

Additionally East et al. report anticipated stigma on the part of parents upon a disclosure of herpes:

*'Bree's feelings of stigma had been exacerbated by how she believed her mother looked at her sometimes. Bree occasionally felt rejected by her mother due to having a sexual infection: 'It all comes back to the way society perceives a person with it [herpes]. And sometimes, I see a bit of disgust in my mother's eyes, and it just makes me feel sh\*\*\*y.'*

(East et al. 2012, p.17) [No asterix in original]

### *2.3.9. Psychological Aspects of HPV Diagnosis*

Previous sections have examined the concept of stigma as a social construct and situated HPV in the context of this social construct. However, in addition to literature examining the sociological sequelae of HPV positivity, the psychological aspects of HPV positivity – arising as a consequence of social stigma – should not be ignored. The first major study examining the psychosocial impact of HPV positivity was published in 1996 (Clarke et al. 1996). Clarke and team recruited 489 individuals from a selected population of 839 subscribers to HPV News, a quarterly journal published by the American Sexual Health Association (ASHA). Responses to the questionnaire showed that 75% of sufferers experienced depression and anger and 66% expressed feelings of shame. In addition, respondents indicated dissatisfaction with information and counselling services that were provided by their clinician. Conversely, a later study by Reed et al. found no significant difference in adverse psychosexual effect in women with occult HPV infection compared to those without (Reed et al. 1999). This may be because the infection was occult – unknown prior to the trial, or ameliorated by the fact that these individuals had few predisposing risk behaviours. Also, the study looked at a psychosexual aspect as opposed to a psychological or psychosocial aspect to the virus. In a meta-analysis of 54 studies covering a range of disorders including: heart disease, cancer, AIDS, diabetes and Huntington's disease; immediate adverse effects (depression and anxiety) were reported in the majority of studies, although for the most part, the duration of anxiety was limited, and positive interventions could be implemented to improve mental health (Shaw et al. 1999).

Since the initial identification of HPV as a necessary cause of cervical cancer, many studies have since shown that there are significant negative emotions attached to the diagnosis of HPV. Kwan et al. (2011) demonstrated that HPV positive women showed higher

scores for stress than HPV negative women. Waller et al. (2007) reported that women with awareness of the role of HPV in cervical abnormalities reported feelings of stigma and shame compared to women who were unaware of the role of HPV. McCaffery et al. (2006) also showed that women interviewed about the inclusion of HPV testing in cervical screening reported feeling anxious, stigmatised and worried about disclosure due to the sexual nature of transmission; whilst Perrin et al (2006) reported how the use of the pejorative terms for description ('warts', 'wart virus') increased feelings of stigma. These feelings, combined with a lack of information about the relatively high lifetime risk of contracting the virus (awareness of which might otherwise reduce stigma) may lead to feelings of shame and guilt amongst patients who have been diagnosed – male or female (Jeynes et al. 2009).

#### *2.3.10. Feelings of Shame, Guilt or Contamination Associated with HPV Positivity*

As noted above, in contrast to the limited sociological literature, there is significant body of literature which exists examining the psychological aspects of HPV positivity. Waller et al. (2007) hypothesised that feelings of shame and stigma would be greater among patients who were aware that HPV was sexually transmitted, and set up an online survey to test their expectations. Their hypotheses proved correct – women who were aware that HPV was sexually transmitted reported higher levels of shame toward a hypothetical HPV positive result than women who were not aware. Scores for shame and stigma were highest in women who were aware of the sexual nature of transmission but unaware of the high prevalence of HPV within the population and the lifetime risk of infection of 1:2 (50%).

McCaffery conducted a series of focus groups amongst ethnic minority women which revealed how HPV positivity was largely associated with infidelity, mistrust and blame; and



that participating in HPV screening implied feelings of mistrust and suspicions of infidelity to their partners and family (McCaffery et al. 2003). It should, however, be noted that these attitudes were produced only by the question of participating in screening and the anticipation of a positive result. These women were not invited for HPV screening at the time of the study.

As well as shame, guilt is a commonly reported emotion following the diagnosis of HPV, or cervical cancer, especially when in possession of the knowledge that disease is caused by a sexually transmitted infection (Nack 2002, 2000). Given the latent nature of the HPV life cycle (Stubenrauch & Laimins 1999), and thus the relative delay between modal age of infection (18-25 years) and the modal age of cancer onset (30-35 years) (Smith et al. 2008), women may assume that they have had HPV for some time, and guilt may be elicited at the thought that they may have transmitted the virus to their partner or partners. The limited efficacy of condoms (Burchell et al. 2006) in preventing the transmission of HPV may compound feelings of guilt.

Alternatively, at the opposite end of the continuum to guilt (a self-imposed construct) is the concept of blame – a construct imposed by others. Where there is a lack of knowledge surrounding the latent nature of HPV, women may report having suspicions that their partner has been unfaithful (Fernandez et al., 2009; Friedman et al., 2007), which can in turn have concomitant negative repercussions on patient relationships, adversely affecting their overall wellbeing. This may in turn lead to a fear of disclosure based on the psychosocial (and possibly physical) repercussions that may follow the disclosure of a stigmatized disease and the uncertainty such a diagnosis may bring (Kosenko et al., 2012).

### *2.3.11. Stigma Following a Diagnosis of Cancer*

The reporting of negative emotions or perceptions of stigma are also found following the diagnosis of malignant disease, which are relevant in the case of HPV as malignant disease of the cervix is the clinical endpoint of persistent HPV infection. Some cultures view illness or disability itself as a stigmatised disease (Scambler, 2009; Saetermoe et al., 2006). Sontag drew attention to the fact that ‘societies need to have one illness which becomes identified with evil, and attaches blame to its ‘victims’’ (Sontag 2002, p.97). Feelings of shame, stigma and models of identity threat have been associated with cancers to which patient behaviours or choices are perceived to have had a possible contributory effect to the disease, for example, smoking and lung cancer (Marlow et al. 2015b; Knapp et al. 2014; Marlow & Wardle 2014; Chambers et al. 2012; Else-Quest et al. 2009; LoConte et al. 2008).

### **2.4. HPV Positivity as a Biographical Disruption**

The literature reviewed in the previous sections has demonstrated HPV to be both a stigmatising condition and one that has negative psychosocial sequelae for affected individuals. This section will examine whether these aspects of HPV positivity can be argued to pose a disruption to biography in affected women. The concept of illness as a disruptive event in the life of an individual was first suggested by Bury (1982). Bury conducted semi-structured interviews with individuals suffering rheumatoid arthritis (RA), concluding that both the symptoms of RA and the effects on an individual’s identity constituted a disruptive event in the individual’s life. At first glance, drawing parallels between chronic illness such as rheumatoid arthritis, diabetes or cancer and HPV would seem an unlikely comparison. HPV is, for example, thought to be transient (Harper et al. 2006; Evander et al. 1995) and may be

asymptomatic (Srivastava et al. 2012; Franco et al. 1999; Villa & Franco 1989) or present in cytologically normal women (Melkert et al. 2009). The usually transient nature of HPV does not sit with the nature of a chronic illness; equally, the asymptomatic nature of HPV does not agree with the chronic pain reported by arthritis sufferers (Fitzpatrick et al. 1988) or the lifestyle interruptions seen in diabetes (Williams, 2000). However, viral persistence over several years has been reported after excision of neoplastic areas by LLETZ or cone biopsy (Louvanto et al. 2010; Nam et al. 2009; Park et al. 2008; Syrjänen et al. 2005; Sarian et al. 2004), viral infection being a chronic entity in these case. In addition to the fears surrounding viral persistence, a number of women present with lesions that are high-risk HPV negative (despite the virus being a necessary cause of the disease) or present with disease recurrence following treatment and a negative 'test-of-cure' HPV test (del Pino et al. 2011), that are thought to be either due to HPV latency or complete integration of the viral genome to the extent that it is undetectable using viral probes (Walboomers & Meijer 1997). Thus the combined effects of HPV-associated stigma on identity - combined with the uncertainty surrounding HPV positivity and the risk of disease recurrence, or false test-of-cure HPV-negativity (due to dormancy) post-LLETZ - make a feasible case for HPV persistence as a biographical disruption.

Bury's model of chronic illness as a biographical disruption (Bury, 1991, 1982) stated that chronically ill individuals had to accommodate changes to various aspects of their lives, as stated below.

- 1) Taken-for-granted assumptions and behaviours;
- 2) Profound disruptions in the explanatory systems used by people – including a fundamental rethinking of biography and self-concept and finally;

- 3) A response to disruption through the mobilisation of resources (Bury, 1982; 1991).

Much of Bury's work on the first point includes the strategic management of symptoms, and this point is the first deviation from this model in the case HPV positivity. Some cases of HPV are determined as a result of the individual reporting symptoms such as dysfunctional bleeding patterns or genital tract discomfort and are thus symptomatic (Gordon et al. 2003). However, the vast majority of cases of HPV-positivity are often asymptomatic (Srivastava et al. 2012; Fife et al. 1987) and are screen-detected, thus do not fit with Bury's description of a 'creeping onset' of symptoms that might be normalised or explained away by the individual. However, once diagnosed (through screening) HPV positivity may adversely affect taken-for-granted assumptions around fertility, or partner fidelity and the estimation of one's self-worth and the taken-for-granted behaviours within relationships (Newton & McCabe 2008a).

However, the second point surrounding the rethinking of biography is pertinent to the case of HPV positivity. Rajaram et al (1997) describe the case of an abnormal Pap smear as a biographical disruption at three levels, to the sense of self; disruption to social relationships with intimates and society at large; and in their daily activities. They also go on to highlight the concept of uncertainty, which Bury (1982) states is a key element in biographical disruption. In the case of cervical abnormalities, the uncertainty was in the inability for medicine to either confirm or exclude disease – in this case genital warts rather than cervical neoplasia. Forss et al. (2001) highlight this uncertainty with the following report from a participant:

*'The doctor said it doesn't positively say I did [have warts], it just says it looks like it... And this is one thing to me that is kinda upsetting. I guess what*

*I'd like to know – couldn't they tell? Don't they take biopsies to tell for sure if it is, or it isn't? So far as I am concerned, I really don't know. And to me, you should be able to know one way or the other and be told.'*

(Forss et al, 2001)

A later study by Forss et al. (2004) reiterates this concept – highlighting that an abnormal cervical screening result did not 'create order' in women's lives as they had perceived it might through taking responsibility for their health in complying with screening – thus demonstrating health-seeking behaviours. East et al. (2010) reiterated this – the act of undertaking screening was a health-seeking behaviour, and to be diagnosed HPV was scant reward for this societal compliance. All of these studies highlight that notification of an abnormal Pap smear had neither confirmed health nor excluded disease. This sense of biomedical limbo led Forss and others to discuss cervical cancer screening as 'a new kind of sickness experience' where one was neither ill nor well, which Forss describes as an experience of liminality.

According to Little (1998) liminality is a sociological term derived from the Latin *limen* first used by anthropologist van Gennep in the study of rites of passage (Thomassen 2009; Hockley 2002). Individuals mid-rite were 'on-the-threshold' of the next stage of their evolution; possessing neither their pre-rite naïveté nor post-rite enlightenment. Use of the term has since come to describe states of uncertainty. Further, Little reports that liminality is a major experience among cancer sufferers through the effects on their identity (from 'normal' to 'cancer patient') and through alienation from loved one due to 'a persistent sense of the boundedness of time'. The study highlighted the sense of loss and the loss of control that patients reported as a biographical disruption felt during the initial stages of diagnosis (Little, 1998). Although not specifically exploring liminality, East et al. (2010) undertook a study on women who had taken up cervical screening and tested positive for

HPV, reporting a disrupted sense of self among participants who had tested positive for HPV. Here though, the disruption was not due to a sense of liminality due to uncertainty over disease, but because the women had assumed that they would not test positive for HPV due to their preconceptions about 'the type of women who contract these infections' which were incompatible with their self-perceived views.

## **2.5. Social Support in Illness**

In the model of illness as a biographical disruption given by Bury previously, the final point of the model is the response to disruption through the mobilisation of resources. In the case of HPV positivity the mobilisation of clinical resources may include a referral to Colposcopy and treatment (in the case of cytologic abnormality) or early recall for repeat cytology in 12 months. In either case, clinical support does not wholly fulfil emotional and social needs of the affected individual, and thus personal resources such as social support may be mobilised. The writings and research of Cohen are major reference points in the field of social support. Early work by Cohen indicated that social support has a role in buffering the stress of illness and also in the aetiology of illness (Cohen 1988; Cohen & Wills 1985). Further works based on his findings have shown that the existence of a secure social network can have important implications for health in cardiovascular disease and diabetes (Compare et al. 2013; Reblin & Uchino 2008; Gallant 2003; Penninx et al. 1997; Uchino et al. 1996). In a systematic analysis of research into major ailments in the last two decades, Braveman & Gottlieb (2014) describe adequate social support as one of the major social determinants of health. According to Heaney & Israel (2008) social support can be described as taking four forms:

- 1) Emotional support, involving the provision of empathy, love and trust;
- 2) Instrumental support – involving the giving of tangible aid and services that directly assist an individual;
- 3) Informational support – in the form of advice, information or suggestions;
- 4) Appraisal support – involving the provision of information useful for self-evaluation that provide, as Heaney and Israel state: opportunities for ‘constructive feedback and self-affirmation’.

(Heaney & Israel 2008; In Glanz et al. 2008, p.189)

Due to the stigmatised nature of both HPV and cervical cancer; the types of social support which would be sought among regular channels – such as partners, family or friends (Barrera & Ainlay 1983) – may be reduced, as the affected woman may not feel able to access these support structures without having to disclose her HPV status due to the effects of social stigma, including rejection and social exclusion that may result (Forbes & Roger 1999). Even among women who anticipate less social stigma, the implementation of these forms of social support – Bury’s ‘mobilisation of resources’ – may be delayed while the woman decides on how to disclose and who to inform of her HPV status. In these situations, the social support provided by peers may be a more appropriate avenue as a ‘first response’.

In order to measure perceptions of social support, Sarason developed and validated the social support scale in the 1980s (Sarason et al., 1983). Research in to social support occurs across many disciplines including anthropology, environmental design, epidemiology, psychology, social work and sociology (Cohen & Syme 1985).

According to Doull et al. (2005), peer support is generally ill-defined – although the general structures of social support (as defined by Heaney & Israel (2008)) – may be fulfilled by peer patients. Dennis (2003b) defines peer support as the ‘provision of emotional, appraisal and informational assistance created by a social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population’ which leads to the ‘sharing of information and experience, mutual counselling and exchange among peers’. The emphasis on shared experience is of particular value among cancer patients (Kuijpers et al. 2013; Hong et al. 2012; Setoyama et al. 2011; van Uden-Kraan et al. 2009; Campbell et al. 2004) including women who have undergone radical surgery as a result of gynaecological surgery (Lloyd et al. 2014). However, again, due to the invisible stigma and reluctance to disclose positivity for HPV, identifying peer patients in real life may not be easy. The development in recent years of online communities offering social support for specific illnesses facilitates the identification of particular peer support groups, and it is the role that online or computer-mediated support can supply that the literature review will now examine.

## **2.6. *The Role of the Internet in Social Support***

The rapid expansion of the Internet and widespread adoption of handheld data devices, broadband and wireless technology has contributed greatly to the accessibility and thus adoption of the Internet in daily life. According to the Office for National Statistics, an estimated 45 million adults had accessed the Internet during the first quarter of 2017 (Jan-Mar 2017) with 89% of households having access to the Web. Of individual users up to 90% of adults aged between 16 and 34 years of age were ‘recent’ Internet users (90% of males,



88% of females) and 78% of the population reported using the Internet on a daily basis. Internet use among older adults (those over age 75) has historically always been lower than other reported age groups, but has increased since the inception of the survey in 2011 – over 41% of adults over age 75 years now use the Internet (ONS 2017a). In contrast, according to the British Audience Research Board (BARB), the estimated daily reach of any/all television channels (on any day in the week 23-29 January 2017) is also approximately 45 million people (BARB 2017) ([www.barb.org.uk](http://www.barb.org.uk), accessed July 17<sup>th</sup> 2017). Thus the reach of the Internet is significant, equivalent in scope to television, and growing; and previous criticisms that have stated that reliance on Internet use is a limitation to research scope are diminishing (Yildiz 2007).

#### *2.6.1. 'Dr Google' – Online Health Information Seeking*

In tandem with the increasing use of the Internet, the use of the Internet to research healthcare information has similarly grown, with the Office for National Statistics reporting that 51% of individuals report using the Internet to access healthcare information, with adults between the ages of 25 and 44 years the most likely to use the Internet for this purpose (ONS, 2016), an increase of 33% since 2007. Eysenbach (2001) attempted to define (and refine) the concept of 'e-health' in an 2001 editorial:

*'It seems quite clear that e-health encompasses more than a mere technological development. ...e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.'*

(Eysenbach, 2001)

A systematic review of the terminology was published in 2005 (Oh et al. 2005), finding 51 separate published definitions of the term – 49 of which mentioned 'health' but largely in the context of 'health-service', 'health-industry' and 'health-sector', indicating that the focus of e-health was largely on health services and systems rather than the physical or mental wellbeing of individuals. Since the origin of the term e-health, the individual health focus has developed, as shown by the ONS report, and has been widely dubbed 'Dr Google' by both the public and in various research papers (Lee et al. 2015; Lee et al. 2014; Robertson et al. 2014; Pías-Peleteiro et al. 2013; Lam-Po-Tang & McKay 2010). Approaches to online support can be divided into two areas – health information seeking and online health communication (Powell et al. 2011).

Since the advent of online health information-seeking, researchers have been undertaking studies to understand the characteristics and motivations of online health information seekers. Cotten (2004) compared offline and online seekers of health information and concluded that the relative age, education and socioeconomic (SE) status of participants followed the pattern of the 'digital divide', with younger, better-educated, higher SE status individuals being more likely to access health information online; and that individuals who reported being physically well were less likely to indulge in health information seeking, indicating that it is an activity undertaken out of necessity rather than

choice. In developing a profile of health information consumerism Dutta-Bergman (2005) noted that the majority of both research and participants took a situational approach, with individuals reporting seeking health information on specific topics such as asthma, AIDS, cancer or diabetes. Rice's (2006) study of two nationally representative datasets – the Pew Internet Survey and the American Life Project indicate that several factors predicted proclivity for health information seeking online including gender (females), engaging in other Internet activities (such as social media use), specific health conditions and supporting another through an illness. Within the field of online health related support the use of communication – to ask questions, to share experiences, to seek emotional reassurance and comfort are some of the primary motivating factors among users (Magnezi et al. 2015; Powell et al. 2011; Armstrong & Powell 2009; Atkinson et al. 2009; Kalichman et al. 2003), indicating that interaction with others is as important as seeking impersonal information.

### *2.6.2. Online Health Communities and Support Groups*

Physical, face-to-face (FtF) peer support groups have a long established history of helping individuals overcome specific problems (Ford et al. 2013; Repper & Carter 2011; Hoey et al. 2008) – well known examples include groups for dependency such as Alcoholics Anonymous and Gamblers Anonymous. In addition to dependency, peer support groups exist for individuals with chronic or life-limiting conditions such as diabetes and cancer (Tang et al. 2011). However, whilst such groups have been shown to be beneficial to individuals in terms of their recovery, the difficulty in accessing groups, or the disclosure implied in the act of joining a support group for a stigmatised condition may deter uptake, as FtF support

groups require a physical venue and visual or physical interaction with other affected individuals. The disinhibiting qualities of the internet may alleviate these difficulties.

In 2004, Suler published his now seminal paper on the disinhibiting power of the internet – known as the ‘Online Disinhibition Effect’ (Suler 2004). The six concepts he outlined are: dissociative anonymity, invisibility, asynchronous communication, dissociative imagination, solipsistic introjections and the minimisation of authority. These factors (particularly anonymity, invisibility and asynchronicity), combined with the increasing popularity, accessibility, ubiquity and anonymity of the Internet may facilitate individuals in receiving peer support through online support groups (OSGs) (Eysenbach et al. 2004a; Eysenbach 2001). Anonymity and invisibility are invaluable to the disclosure of sensitive or stigmatized information, and the simultaneous synchronous/asynchronous nature of online support allows both the exchange of messages in real time and the acquiring/assimilation of information at the participant’s own pace (White & Dorman 2001).

### *2.6.3. Theories of Peer Support – Online and Offline*

Peer support differs vastly from clinical support, but the role it has to play should not be underestimated (Davis, 2010). Clinical support tends to deal with the quantitative aspects of a disease process – the chances of survival, the stage of disease and the options for treatment. In contrast, peer support is based on the experiential knowledge of diagnosis, treatment and recovery (Dennis, 2003a). The underlying concepts of peer support are based on four factors: experiential knowledge, social support, social learning theory and social comparison. Individuals wishing to learn about the lived experience of diagnosis, treatment and recovery can learn from peer patients (Solomon 2004; Dennis 2003b). In addition peer

support groups may increase individuals perceptions of social support, both online (Barrera et al. 2002) and offline (Helgeson et al. 2000). Social support has been found to be associated with better recovery during a disease process (Von Ah et al. 2007). Social comparison can be helpful in terms of self-recognition and acceptance following a diagnosis and a disrupted sense of self (East et al. 2010). Beaudoin & Tao (2008, 2007) demonstrated that both the Internet and social media groups have been beneficial to the psychological health outcomes of cancer patients in terms of both information-gathering and social/emotional support. Beaudoin & Tao found that cancer patients who went online for information regarding their condition and who sought emotional support from peer patients reported lower stress and depression scores and better coping scores than non-internet users. The use of dedicated sites and forums for women diagnosed with HPV could be very beneficial for patients who wish to get more information or discuss their fears and feelings with others who may be able to provide emotional support and reinforcement in a private environment within their own homes.

## **2.7. Summary of Literature Review**

The reviewed literature has demonstrated the existence of a model of the self which is reflexive and responsive to feedback based on the perceptions and actions of others; composed of identities constructed through the habitation of socially negotiated roles and the membership of chosen social groups. The possession of what Goffman describes as ‘a discrediting social characteristic’, such as a stigmatised, sexually transmitted infection may present a threat to identity if disclosure of the condition is likely to result in rejection or exclusion from the individual’s chosen social groups. The structures and models by which stigma can be defined lead to the formation, in the affected individual’s social world, of three populations – the own (others who share the discrediting characteristic), the wise (individuals who do not share the characteristic but are sympathetic to the condition) and ‘normals’ – unaffected individuals who are unaware of the stigmatised person’s condition. The affected individual may wish to draw on social support from all three groups at different times and in different ways – the ‘own’ may fulfil the roles of support through sharing experiences; the ‘wise’ may extend support through providing acceptance; and the ‘normals’ may unwittingly provide support by allowing the affected individual to ‘pass’ as a normal. Uncertainty due to liminality or altered sickness experience inferred by the use of a screening tool on an ostensibly healthy population in tandem the uptake of screening as a health-seeking or health-confirming behaviour, and the anticipated or felt stigma following HPV-positivity, uncertainty over relational issues such as fidelity or reproductive health and carcinogenesis all contribute in essence to the constitution of HPV as a biographical disruption. Use of peer support accessed online negates many of the issues of location, mobility and disclosure (through anonymity) that non-internet users may face.

## **2.8. Research Questions**

The literature review examined in previous chapters led to the formulation of the following research questions:

1. Does a diagnosis of HPV or HPV & CIN represent a biographical disruption?
2. If either diagnosis constitutes a biographical disruption, what factors contribute to this?
3. What role(s) might online support play in the management of the self, stigma and biography during the diagnostic and treatment arc?

## **Chapter Three – Methodology**

### ***3.1. Introduction***

This section will commence with a discussion of the philosophies underpinning the research, the guiding theoretical perspectives and epistemology that informed the methodology and why these were the most appropriate for the project. As an early-career researcher trained in a discipline grounded in a positivist philosophy and quantitative methodologies – and therefore new to the practical aspects of qualitative research (outside of early modules offered in the taught phase of the degree); the interchangeable and conflicting use of terminology in articles and textbooks was initially confusing. Early conversations with the supervisory team centred on the nature of research philosophies and methods – in short, was phenomenology a philosophy or a research approach, or both? Where should it be positioned within the final draft of the chapter? The answers to these questions might seem obvious to a practitioner experienced in qualitative or mixed-methods research, but as a result of this confusion, early drafts of the chapter lacked clarity and an ordered narrative. The use of the organising framework expounded by Creswell (2010) was very helpful in categorising and clarifying the various ideas and terms encountered during the preparatory phase of this study, and as such will be used to structure the methodology chapter.

Creswell organises research according to overarching worldviews. These worldviews are described by various characteristics, which are given in the table overleaf.



Post-positivist Worldview	Constructivist Worldview	Participatory Worldview	Pragmatist Worldview
Determination	Understanding	Political	Consequences of actions
Reductionism	Multiple participant meanings	Empowerment and issue oriented	Problem centred
Empirical observation and measurement	Social and historical construction	Collaborative	Pluralistic
Theory verification	Theory generation	Change oriented	Real-world practice oriented.

Table 3.1: Basic characteristics of four worldviews used in research (from Creswell 2010, p.40).

If the researcher were to orientate research for this current study on the basis of aspirations, Creswell's stance of taking 'multiple stances from multiple world views' would be most applicable. The first phase of the research was originally planned and written from the stance of a biomedical scientist for whom positivism was the default approach (Broom & Willis 2007). The second phase of the research is largely constructivist; and thus pragmatist aspects of mixed methods research should also be considered (Feilzer, 2010). In addition, from the perspective of a practitioner in cytology, elements can be borrowed from the participatory worldview, as the researcher would like the research outcomes to be empowering (for the participants) and because the research questions are issue-oriented and problem-centred. As the outcomes and recommendations might appeal to various audiences including future patients, clinicians and policy-makers; the research could also be described as oriented toward real-world practice. However, to attempt to undertake and understand multiple worldviews (at a first attempt in mixed methods research) would be ambitious, foolhardy and would lead to a large, unwieldy project that attempts breadth without depth. Therefore the approach used to organise the research will focus on the constructivist worldview which informed the concepts of self, identity and stigma discussed in Chapter 2, and the interview phase of data collection.

Worldview Element	Post-positivism	Constructivism	Participatory	Pragmatism
Ontology (What is the nature of reality)	Singular reality  (Researchers reject or fail to reject hypotheses)	Multiple realities  (Researchers provide quotes to illustrate different perspectives)	Political reality  (Findings are negotiated with participants)	Singular & multiple realities  (Researchers test hypotheses and provide multiple perspectives)
Epistemology (What is the relationship between the researcher and the researched)	Distance and impartiality  (Researchers objectively collect data on instruments)	Closeness  (e.g. researchers visit participants at their sites to collect data)	Collaboration  (e.g. researchers actively involve participants as collaborators)	Practicality  (e.g. researchers collect data by 'what works' to address research question)
Axiology (What is the role of values?)	Unbiased  Researcher uses checks to eliminate bias)	Biased  (Researchers actively talk about their biases and interpretations)	Negotiated  (Researchers negotiate their biases with participants)	Multiple stances  (researchers include both biased and unbiased perspectives)
Methodology (What is the process of research?)	Deductive  (Researchers test an <i>a priori</i> theory)	Inductive  (Researchers start with participants' views and build 'up' to patterns, theories and generalizations)	Participatory  (Researchers involve participants in all stages of the research and engage in cyclical reviews of results)	Combining  (Researchers collect both quantitative and qualitative data and mix them)
Rhetoric (What is the language of research/)	Formal style  (Researchers use agreed-on definitions of variables)	Informal style  (Researchers write in a literary, informal style)	Advocacy/change  (Researchers use language that will help bring about change and advocate for participants)	Formal or informal  (Researchers may employ both formal and informal styles of writing)

Table 3.2: Elements of worldviews and implications for practice (from Creswell 2010, p.41).

## **3.2. Ontology**

### *3.2.1. Objectivism/Realism*

Ontology describes the nature of reality (Dillon & Wals 2006). In table 3.1 Creswell describes four worldviews upon which research may be based: post-positivist, constructivist, participatory and pragmatist. These are then further differentiated on the basis of the elements from which they are composed (as shown in table 3.2). Kuhn's seminal work *The Structure of Scientific Revolutions* described different knowledge schools or branches as 'paradigms' (Kuhn 2012, p.11). Kuhn describes a paradigm as 'the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed'. Guba (1990) explains that paradigms can be characterised on the basis of assumptions about their ontology (the theory of reality, or being); their epistemology (the theory of knowledge) and their methodology (the means by which we find things out). Creswell adds axiology (the nature of values), and the form of language used in communicating findings, to this list. Thus on the basis of these elements, paradigms determine the nature of knowledge existence and how it may be generated in a valid manner.

Echoing Kuhn, Higgs posits that a paradigm is composed of a 'set of beliefs, conventions and assumptions that define what meaningful and relevant research questions can be asked, what constitutes a meaningful answer and how the researcher can go about providing an appropriate answer' (Higgs 2001, p.154). These elements shape the research arc by informing the manner in which the researcher views and determines reality and the way in which variables are known and measured within that reality. Applying Creswell's framework to this research project – the study is situated in a constructivist ontology – the

elements examined in the literature review (self, identity, illness, stigma and social support) have all been shown to be socially constructed (Gergen 2011; Conrad & Barker 2010; LaCoursiere 2001; Crocker 1999). Constructivist ontology informs the interpretivist epistemological or theoretical perspective. This interpretivist perspective focuses on establishing how meanings emerge and are manifested and applied to social worlds (Walter 2013, p.17), and this informed the research approach of phenomenology. In turn, phenomenology studies the structures of consciousness as experience from the first-person point of view (Smith, 2017). This approach, in turn, informs the research methods employed – namely questionnaires and interviews.

Positivism – the philosophical approach which is espoused by and fits (ontologically and epistemologically) with the natural science disciplines, including biomedical science – holds that the researcher and the external ‘world’ of discovery (the object under study) are completely separate. As a research philosophy, positivism owes its intellectual origins to the writings of Comté (Howell 2013, p.32). However, whilst holding a similar ontological view, advocates of post-positivism hold that there is a single reality, existing objectively and independently of human perception (Crotty 1998, p.12); that ‘the truth is out there’ and that research must work to uncover this truth independent of any bias that might be introduced by subjective reasoning or researcher perception induced by gender (Kane & Macaulay 1993), race (Cotter et al. 1982) or type of interview (Hansen, 2006). Objectivist ontology *‘holds that meaning, and therefore meaningful reality, exists as such apart from the operation of any consciousness’* (Crotty 1998, p.8). The equivalent area in Higgs’ model is the ontology of the empirico-analytical paradigm (Higgs 2001, p.156). For both authors, the nature of this paradigm embraces positivist and empiricist philosophies; theories are pre-formulated and verified by testing hypotheses through deductive reasoning. Objectivist

ontology and a hypothetico-deductive approach to theory verification using quantifiable methods have historically informed the natural science disciplines such as physics and chemistry (Higgs 2008, p.155); for example, the empirico-analytical paradigm has historically dominated the fields of healthcare and biomedical research. The researcher's day-to-day discipline – biomedical science – favours an objective ontology (Broom & Willis 2007, p.17). This is largely due to the fact that the researcher's practice – cytology – operates according to Bayesian constructs (Reid, 2017) disease is either present or absent and, if present, malignant or non-malignant. Here, the presence of disease is an objective truth that must be discovered, or excluded. Thus, the human papillomavirus fits with Crotty and Higgs' definitions of objective knowledge in that the reality of the virus as an entity exists independently of its perception both by the individual and by a population of individuals – HPV being asymptomatic in the majority of cases means that the virus can be contracted and spread independently of an individual's perception of it.

As with HPV positivity, carcinogenicity from persistent HPV infection exists independently of our perception of it (i.e. an individual can be infected without perceiving the fact, and may develop pre-cancerous and cancerous changes prior to being aware of the fact). HPV positivity can be operationalised as a variable (as a positive or negative test result), quantified and measured as viral load (Constandinou-Williams et al. 2010). HPV antibodies can be detected, quantified and measured to determine vaccine efficacy (Dillner et al. 2011). All of the features of the virus described above – detection methods; determinants of mutagenicity, carcinogenicity, immunogenicity are quantifiable and can be scrutinised by quantifiable methods that support an objective ontology. However, according to Higgs (2001, p.155), once the research gaze focuses on interpersonal relationships, the examination of personhood or the construction of meanings, as with this study, the model of

objective ontology and quantifiable methods becomes increasingly inadequate because these factors are subject to constructions and interpretations that vary. Thus while the fact of HPV positivity is objective, the effects on personhood of knowing one is HPV positive become subject to social constructs, and so the research gaze turns to constructionism.

### 3.2.2. Constructionism

Crotty applies the following definition to constructionism:

*'All knowledge and therefore all meaningful reality as such, is contingent upon practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context. ...In the constructionist view, as the word suggests, meaning is not discovered, but constructed.'*

(Crotty, 1998, p.42).

Greenwood offers the example of a chair to illustrate the difference between physical and social phenomena:

*'Physical and social phenomena...differ in one essential respect. Chairs may exist independently of our knowing that they do; our knowledge of the existence of chairs is not constitutive of their existence. In contrast, social phenomena do not exist independently of our knowledge of them...Social realities, therefore, are constructed and sustained by the observation of the social rules which obtain in any social situation by all the social interactors involved...Social reality is, therefore, a function of shared meanings; it is constructed, sustained and reproduced through social life.'*

(Greenwood, 1994, p.45, cited in Crotty, 1998 p54-55)

The concept of HPV fits into this idea of physical and social phenomena differing in terms of their existence independent of our knowing of them. The physical, biomedical, pathogenic phenomena of HPV can exist, asymptotically infecting and affecting epithelial cells independently of the individual being aware of it. However, the existence of the social

phenomena surrounding HPV positivity – stigma (Waller et al. 2007), shame (Kim 2012), anxiety over mortality (Maggino et al. 2007), disclosure and social rejection (McCurdy et al. 2011; Brown et al. 2007) cannot exist, or at least the reality of these phenomena cannot affect the individual until s/he is aware of the existence of the virus within their body.

### *3.2.3. Relativism*

On the basis of embracing a constructionist worldview, the ontological assumptions of this study are relativist in nature. According to Denzin & Lincoln (quoting Guba, Lincoln and Lytham) constructionism adopts: ‘a relativist ontology, a transactional epistemology and a hermeneutic, dialectical methodology’ (Denzin & Lincoln 2017, p.212). Literature examined in previous chapters supports these ideas – the concepts of self and identity, and also those of threats to identity (such as social exclusion and rejection) have all been demonstrated to be constructed on the basis of social transactions. Similarly, the effects on identity (such as stigma and shame) have also been shown to be constructed on the basis of social transactions and interactions (Major et al. 2005; Pettigrew 1985). Thus, it follows that a research philosophy that supports the notion of a constructed and negotiated reality would be the best fit for this research. In addition, this study thus assumes that the reality of HPV positivity is unique and subjective to each participant and should be determined ‘according to each individual’s personal, cultural and experiential background’ (Eatough & Smith 2017, p.193).

### **3.3. Theoretical Assumptions: The Interpretative Paradigm**

The interpretive paradigm sits within the constructionist epistemology; and recognises that meaning is a human construction (Maines, 2000). According to the interpretive paradigm, the meanings that individuals attribute to things in the world are not only constructed but contingent. Constructed meaning is contingent, reliant and relative to context – constructed meaning may be affected by/depend on spatial, cultural or historical features that individuals apply to the meaning-making act (Harré, 2002). Thus, the scope for variation in the construction of valid meanings – both between individuals, and within individuals (because meanings can change over time according to circumstances) is infinite. It is the need to examine the individual construction of meaning and experience which informs the research approach of phenomenology.

### **3.4. Research Approach: Phenomenology**

The term phenomenology is derived from the Greek *phainesthai* (to flare up/to show itself), *phainómenon* (that which appears) and *lógos* (to study) (Moustakas, 1994) and thus literally means ‘the study of that which appears’. The Stanford Encyclopaedia of Philosophy lists phenomenology as one of the main branches of philosophy, along with ontology (the study of ‘what is’, ‘being’ and the nature of reality); epistemology (the study of *how* we can know ‘what is’); logic (the study of reason); ethics (examining right and wrong action). The same source further broadens Moustaka’s definition, describing phenomenology as: ‘the study of consciousness as experienced from the first-person point of view’ (Steup, 2016). Moran re-iterates this concept in more depth, at the beginning of his *Introduction of Phenomenology*, telling us that:



‘Phenomenology is best understood as a radical, anti-traditional style of philosophising, which emphasises the attempt to get to the truth of matters, to describe *phenomena*, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer.’ (Moran 2000, p.4).

LeMay & Pitts (1996, p.27) re-iterate the focus on experience – defining phenomenology as ‘how we experience the world’. Within the context of this research, phenomenology questions and examines the experience of being HPV-positive, the diagnostic and treatment process and the use of HPV-related online support.

According to McAleer (2005), the development of phenomenology was the defining philosophical movement of the last century. However, whilst the 20<sup>th</sup> century saw the most developments within phenomenology, the origins of the movement are far older. According to Moran (2000, p.200) the philosophy of phenomenology can be traced back to Aristotle. Whilst not specifically mentioned in his writings (specifically *De Anima*), Aristotle’s discussions on different modes of being ‘...as property, being in the sense of categories, being in the sense of possibility and actuality’ were among the first speculations on being, although the term as recognised today would not appear for centuries. In fact, it was nearly two thousand years before the term ‘phenomenologia’ was first introduced by German theologian Christophe Oetinger in 1736 in reference to the nature of God (Davis & Steinbock 2016). Religion and theology would later become common topics for modern scholars such as Scheler and Levinas also used the term phenomenology in reference to theological texts and refined their ideas of phenomenology through the prism of religion (McAleer, 2005). Though introduced in the mid-18<sup>th</sup> century, the term phenomenology was first used in modern philosophical literature by Hegel – in his work *Phenomenology of the Spirit* – but did not come into common usage until Edmund Husserl adopted the term in his 1901 work

*Logische Untersuchungen* ('Logical investigations') (Husserl 2001, p.xviii). Today, the modern practice and pursuit of phenomenology is generally considered to be based on the foundations of Husserl's work (Husserl 2001, p.xxxvi).

### **3.5. Svenaeus: Towards a Phenomenology of Illness**

As this study makes particular reference to illness, it is important to link phenomenology and the Heideggerian nature of being with a phenomenology of illness. Unfortunately, neither Husserl in his work on the lived-experience nor Heidegger in his efforts of being-in-the-world focused much attention on the concept of illness and its impact on being, but other authors have chosen to exercise Heideggerian perspectives on these topics. Svenaeus (2000) dissects some of the Heideggerian terminology, specifically asking 'what is it like...from the patient's perspective...to suffer from illness' – focusing his attention on the individual as an ill person as well as a diseased organism. In order to do this, Svenaeus turns to the Heideggerian concept of *Umheimlichkeit* literally 'un-home-like-ness'; suggesting that the unwell individual, whilst being in familiar surroundings, suddenly feels unfamiliar and 'not at-home' with his/her body or the functions that it previously undertook (but no longer performs) or new processes that must be executed that were not previously required (such as rehabilitation post-stroke, or daily injections following a diagnosis of diabetes).

In addition to a new unfamiliarity with the body, Svenaeus also suggests that there is a new anxiety present from the point of diagnosis which is separate from the Heideggerian concepts of *Angst* (the background existential anxiety of an authentic existence) and also from the anxiety that Heidegger termed *Sein-zum-Tode* ('Being-towards-death'). This 'being-toward-death' is not necessarily a literal decease, but the call or need to re-evaluate one's

being from the standpoint of an ending (Wheeler, 2016). With respect to HPV, the contraction of a stigmatised virus that predisposes an individual to cancer, and the anxiety surrounding both disclosure and the possible transmission to will serve to increase existential anxiety. As HPV asymptomatic, the discussion surrounding the lived-experience will be different to the discussion of the lived-experience of an amputee, or an individual living with cancer, or one living with a chronic disease such as diabetes. This is principally due to an absence of symptoms that might be encountered with other conditions (such as a phantom limb, or the pain and sickness associated with cancer treatment, or the experience of hypoglycaemia). The phenomenology of the lived experience is more likely to be due to an unhomelikeness or anxiety caused by a forced re-evaluation of the self (in terms of self-worth or one's estimation of one's sexual or reproductive self, or a foreshadowing of mortality (Svenaesus 2011) or anxiety about changes to others' perceptions of one.

Svenaesus also makes the point that, as part of the process of treatment, the healthcare professional has a responsibility to help the individual suffering unhomelikeness through illness to either regain the original feeling of homelikeness or familiarity through curative processes or to help the individual achieve a feeling of homelikeness through re-adjustment to new circumstances or states. This process of achieving familiarity with the self or of returning 'home' within the body is analogous to resolving the biographical disruption that follows a diagnosis of an illness or the occurrence of a life-changing injury or event. Within the context of this research the act of narrating either lived experiences or the biographical work involved in acceptance may allow the narrator to achieve perspective on or acknowledge a 'returning home' to the self as lived now.

### **3.6. A Critique of Phenomenology in Qualitative Healthcare Research**

Although discussion of previous literature in the field of phenomenology demonstrates it is the most appropriate research approach for this study, it is important to be mindful of critics to the technique, in order to avoid the pitfalls that invoked criticism. The use of phenomenology in healthcare research was established in the 1980s, when Benner established a method of interpretive phenomenology in nursing (Petrovskaya, 2014), where it is used to elucidate the lived experiences of patients (Crotty, 1996). Literature discussed in this section is devoted to the critique of the use of phenomenology in nursing, as this is the most prominent healthcare field in which phenomenology has been used as a research method.

The focus on human existence, patient experience, and the ‘accounts of time, body, space and human relations as people experience them, altered by health and illness’ (Matua & Van Der Wal 2015; Matua, 2015; Earle 2010) are all valued as enabling and developing healthcare in an era dominated by holism and evidence-based practice. However, this explosion in phenomenological healthcare research is still evolving, and may be subject to limitations arising through amateur attempts or as according to Ray (1994) a lack of understanding of phenomenology and its philosophical underpinnings. Paley has been a vociferous critic of the use of Husserlian phenomenology in healthcare research stating:

*‘...their methods do not entitle them to lay claim to anything resembling ‘objectivity’ or generalisability, or ‘reality’, or theoretical abstraction. Like other researchers, they want to talk in generalisable terms about reality; they want to be objective, they want to do theory. But they are saddled with a philosophy that is disabling, because it says they can only talk about perceptions, and meanings, and uniqueness.’*

Paley (2005)

In previous works, Paley has scathingly concluded that nursing phenomenology lacks credible instances of what and how 'essences' are derived and that 'the project of identifying an 'essential structure' of a phenomenon, typically adopted by nurse researchers who cite Husserl as an authority, comes close to being unintelligible.' (Paley, 1997). Other authors critiquing the use of phenomenology are less outspoken but do address the question of undertaking successful phenomenological research in nursing (Morse & Field 1996, p.194). Crotty, whose work on research philosophy was discussed at length in the previous chapter, has also voiced a cautionary tone in the use of phenomenological research methods in nursing research, stating that nursing phenomenology is too subjective. Whilst this may seem an odd accusation to level at qualitative research, he discusses at length the distinction of and interplay between objectivity and subjectivity in the introduction to his text *The Foundations of Social Research* (1998, p.7). In addition, Crotty accuses nurse researchers of 'dressing their studies in 'Heideggerian livery'' rather than genuinely attempting to apply Heideggerian philosophy to their researches (Crotty 1996, p.76).

### **3.7. Research Design**

Having thoroughly examined the research philosophies, theoretical assumptions and approaches considered most apposite to the research, the research design must be appraised. There is ongoing debate as to whether the approach is simply a combination of the two (historically opposed) quantitative and qualitative paradigms (Denscombe 2010, p.10), or a distinct research paradigm in its own right. This argument formed much of the substance of Creswell's 'paradigm debate period'. Johnson and Omwuegbuzie (2004) contend that mixed-methods research occupies a unique third paradigm or 'chair', sitting

between quantitative and qualitative endeavours or –in the words of Greene (2007, p.8) – a third ‘community of practice’; whereas other authors argue that mixed-methods research is merely a blending of the most advantageous aspects of the quantitative and qualitative paradigms (Mertens 2005, p.4). The decision to begin the project with quantitative data is largely a reflection of the researcher’s own scientific background – quantitative data being a natural choice for an author educated in a natural science/positivist tradition. In addition to fulfilling the research need and the recommendations of the examiners, the decision to widen the scope of the research to include qualitative data also represents the author’s own evolution into a more rounded researcher and practitioner.

### *3.7.1. Mixed Methods Research: Follow-Up Explanations Model*

Whilst mixed methods research has been described by Denscombe as any method that combines two or more research methods (Denscombe, 2010, p.10), this combination is not haphazard. Any research model that combines two or more methods places emphasis on the structure of that model – the sequence in which one method follows another (Tashakkori & Teddlie 2010, p.27). In the case of this study, the quantitative data was gathered first, and this fact largely dictated the structure of the mixed methods model that followed.

Creswell et al. (2003, p.73) describe four designs of mixed methods models: triangulation, embedded, explanatory and exploratory designs. According to their rationale, the model used for this research study cannot be described as a triangulation design, as the data collection period did not occur in a single phase – the quantitative and qualitative data were not collected concurrently. Although an exploratory study in nature, the research is not of the exploratory design, as qualitative data was not collected first. At first glance, the

embedded and explanatory models would seem difficult to differentiate in the context of this project, as both models may involve two-phase data collection; and may allow for the collection of quantitative data in the first phase, as in this study. However, the two structures differ in terms of the weighting given to each type of data. The embedded model describes research where the secondary data type (in this case, qualitative data) plays a more supplemental/supportive role rather than being given equal weighting with the quantitative data. Therefore according to the descriptions set out by Creswell et al. (2003, p.73) this mixed methods study has an explanatory design model, as the data are collected according to a two-phase model (sequentially, with qualitative data being collected in the second phase, to explain or enrich quantitative data) and with equal weighting being given to both data types.

### *3.7.2. Advantages of an Explanatory Mixed Methods Design*

According to Denscombe (2010, p.11) mixed methods research refers to: ‘a research strategy that crosses the boundaries of conventional paradigms by deliberately combining methods drawn from different traditions with different assumptions’. At its simplest, a mixed methods strategy combines quantitative and qualitative methods. As a scientist educated in a largely positivist tradition, the collection and analysis of quantitative data was not alien, and in devising the original project the use of a questionnaire to gather the quantitative data seemed the most natural method of achieving this objective. The questionnaire as an instrument of collecting survey data was relatively cheap, swift and a large audience of individuals could be approached in order to achieve sufficient statistical power for the analysis phase. However, the structure of the instrument and the data obtained were very much researcher-led, comprising questions the researcher wanted to

ask, rather than the questions or issues the participants wished to answer or expand upon; and thus, researcher bias may have been introduced.

Qualitative data gathered by performing and transcribing electronic interviews will offer thick description of subjects first introduced in the questionnaire – namely the elucidation of women’s further information needs, their perceptions of social support and the benefits derived from the membership of online support groups devoted to HPV awareness. In addition, the act of narrating their experience will allow the participants to construct, re-construct or revisit their own meanings surrounding diagnosis and the lived-experience of being HPV-positive.

The main advantage of a mixed methods approach is that the researcher gains a better understanding of the topic under study by combining methods than by either research approach used alone (Denscombe 2010, p.11). In addition to research outcomes, this aspect of mixing methods is immensely valuable to the author’s professional practice as increased understanding of the lived experiences of HPV positive women can be used to help inform training protocols for primary healthcare givers and literature enclosed with screening invitations. The greater understanding obtained is gained by viewing the research problem from multiple perspectives, rather than relying on a single approach, viewpoint and data collection method. Multiple viewpoints allow for different methods of data collection and thus richer data and more opportunities for analysis. In addition to richer data, multiple perspectives and data collection methods allow for data triangulation – cross verification of findings by using more than one source for the data through ‘convergence, corroboration and correspondence of results from the different methods’ (Greene et al. 1989).



### *3.7.3. Disadvantages of a Mixed Methods Design*

In addition to the advantages of a mixed methods approach, it is important, given the timeframe of the research, to consider the disadvantages. The only real disadvantage encountered during the evaluation of research approaches was the aspect of time, as mixed methods research tends to consume both time and resources. However, as the majority of the quantitative data had been gathered and analysed during the initial stage of the project, this factor did not present a significant issue.

## **3.8. Methodological Considerations**

### *3.8.1. Choice of Qualitative Data Collection Methods*

As the study was a mixed methods endeavour, and aimed to gather information surrounding the online and lived experiences of women with HPV, various collection methods were considered to determine the best means of gathering this type of data. The quantitative arm of the study will utilise a survey questionnaire, so the use of another such instrument would be of limited use in reporting individual experiences; would be researcher-led in terms of the content and order of the questions and subsequently the responses, though belonging to the participants, would be influenced by the researcher (Choi & Pak 2005); and therefore invalidate the concept of mixed methods research. Thus, in order to allow the study to be a truly mixed methods undertaking, a complementary method of data collection was required to allow the advancement of participants' ideas and narratives around the research topic, to harmonise with the researcher-led questionnaire.

The aims of the study required entering in to the lifeworlds of participants and, according to Opdenakker (2006) and Dickson-Swift et al. (2008), qualitative research interviews were considered the most appropriate, efficient, sensitive and time-sensitive method of collecting this type of data. Case studies and ethnography were both considered during the research design process as both allow descriptions of everyday life and practice (Tashakkori & Teddlie 2010, pp.36, 42). However, although the research project aims to examine the everyday lives and experience of HPV-positive women, the individuals of a sample population may not necessarily share the same geographical locations or social groups; thus outside of a virtual environment are unlikely to live in close enough proximity to make ethnographic study feasible, and virtual focus groups may be open to the same privacy and confidentiality issues as actual focus groups. In addition, as the researcher works full-time, the prolonged and repeated contact required for successful case study was similarly not feasible. A variation on ethnography, 'netnography' – a specialised form of ethnography directed to the study of online groups was considered for the examination of themes and dynamics within groups. This idea was abandoned due to possible ethical issues around observing individuals online without their knowledge (Kozinets 2015, pp.127–129).

### *3.8.2. Qualitative Research Interviews*

Creswell (2007a) argued that interviewing is perhaps the oldest, most recognised, familiar and utilised method of qualitative data collection (although Gubrium & Holstein (2002, p.4) added that the interviews practiced today did not exist forty years ago. However, more recently, the social prevalence and ubiquity of interviews in everyday life – through television, radio, social and printed news media, blogs and vlogs – has resulted in the rise of

the 'interview society' (Silverman 2006, p.30). Arksey and Knight have suggested that interviews are not a specific method but 'a family of approaches which have one thing in common – conversation between people in which one person has the role of researcher' (Arksey & Knight 1999). Kvale (2006) reiterated this, dubbing the interview 'a professional conversation', noting that such conversations are considered 'a fundamental part of the research process' (Kvale & Brinkmann, 2009; Kvale, 1996). Patton stated that '*the power and purpose of interviewing is 'to find out what is in and on a person's mind..., to access the perspective of the person being interviewed..., to find out from them things we cannot directly observe'*' (Patton, 1990 p.278; cited in (Arksey & Knight 1999, p.32). In this family of approaches, Novick (2008) considered face-to-face (FTF) or on-site interviews to be the gold standard method for gathering data on participant's interpretations of their lived experiences. Other forms of interviews, such as postal and telephone interviews (Mealer & Jones 2014; Edwards et al. 2002) have been utilised successfully, both historically and in the recent past. The FTF qualitative research interview entails meeting with a participant for a specified/pre-arrange length of time, in an environment which is private, neutral and unthreatening to the participant.

### *3.8.3. Building Rapport in Interviews*

Perhaps one of the most difficult tasks during an interview is gaining enough trust and rapport from the participant in a very limited time; the opening minutes of the interview process are very important to build up sufficient trust in order that the participant will trust the interviewer enough to give truthful, meaningful answers to questions, in order that a 'real' experience can be captured (Henderson & Gilding 2004). If the effort to gain trust and

rapport is begun too early, or the conversation is too fast, the rapport-building process can feel rushed or forced, and reduce the amount of trust the participant has, and consequently have a deleterious effect on the whole interview and resulting transcript (DiCicco-Bloom & Crabtree 2006). Conversely, if rapport is not built until the final minutes of the interview, the interviewer has no way of knowing whether the participant has disclosed a true personal experience or instead constructed an experience based on their perception of a socially desirable response (Presser & Stinson 1998, Nederhof, 1985). This dilemma is particularly important during semi-structured or unstructured interviews and interviews surrounding sensitive topics such as health, sexual behaviours and stigmatised conditions. Peter and Valkenberg have researched and written on the subject of obtaining trust and achieving rapport during the online data collection, focusing on the issue of sensitive topics such as the disclosure of highly personal information (i.e. disease status, or the discussion of stigmatised behaviours such as substance abuse). They reported that the use of 'forgiving' language during the introduction of an online survey increased the amount of sensitive information disclosed by respondents who had scored highly on social desirability scale. These individuals reported more sensitive behaviour than individuals who scored low on social desirability scales (Peter & Valkenburg 2011).

#### *3.8.4 Reciprocity*

As the research population were recruited from online sources, to help build rapport, and in order to demonstrate both trust and reciprocity, the researcher decided to use her own Facebook profile in order to approach gatekeepers, and through gatekeepers, participants. The use of a faceless profile page, using a professional title (such as 'HPV

Facebook Study') and the De Montfort University logo was considered (ethical approval had been granted for the use of the University logo), but abandoned as too impersonal, formal and unlikely to foster trust. Duncombe and Jessop (2002) quote Glesne and Peshkin on the ethical naïveté of gaining trust:

*'Rapport is tantamount to trust, and trust is the foundation for acquiring the fullest, most accurate disclosure a respondent is able to make... when you are warm and caring, you promote rapport, you make yourself appealing to talk to, and, not least, you communicate to your respondents, 'I see you as a human being with interests, experience, and needs beyond those I tap for my own purposes'... In an effective interview, both researcher and respondent feel good, rewarded and satisfied by the process and the outcomes. The warm and caring researcher is on the way to achieve such effectiveness.'*

*Glesne & Peshkin, 1992 cited in Duncombe & Jessop, 2002, p110*

The quote given above is included to demonstrate that the researcher was aware of the fine line between honesty and reciprocity and the ethics of 'faking friendship' (Duncombe & Jessop 2002, p.108). Honesty and reciprocity were paramount in view of both the sensitive nature of the topic (Fahie 2014) and the question of power within the research interaction (Oakley 2015). If the aim of the research was to ask participants to share details of their day-to-day lives with HPV, it seemed reasonable and reciprocal to allow potential participants to examine the day-to-day life of researcher before they committed to the interview process. In terms of preserving confidentiality, access to the identities of the researcher's family and friends was restricted in order to protect their privacy; and possible contentious posts (political views, photographs of friends and/or children) were similarly restricted in order to keep the view of the researcher as neutral as possible. There were some aspects of the researcher identity that could not be hidden that may have affected participants' perceptions of the researcher – such as race, gender and an indication of SE

status, but to hide these by creating a fictional identity to minimise the interviewer effect (Davis et al 2010; Kane & Macaulay 1993; Cotter et al. 1982) would have been as unethical as the 'fake friendship' that Duncombe & Jessops object to. The use of the researcher's personal Facebook profile to establish trust and rapport; along with a position as one of the 'wise' (to use Goffman's terminology (Smith 2012; Nack 2008, p.56; Goffman 1990a p.23)) due to a healthcare background lead to the consideration of the researcher's position as an insider researcher. Methodological considerations associated with insider research are discussed in section 3.8.6.

#### *3.8.5. Electronic Interviews*

Although FTF interviews are established as the gold standard technique in qualitative research interviews, there may be occasions where they are not suitable – where the sensitivity, privacy or perceived stigma surrounding the discussion material may make individuals unwilling to meet (Paechter 2013). Physical or other disabilities may make it difficult for the participant to travel to a neutral place (Braun & Clarke 2013, p.82); the geographical spread of individuals may also add difficulties in reaching all participants for a physical interview. As mentioned in Chapter 2, the rapid growth of the Internet and online/communication technologies has led to other forms of interview. Braun and Clarke (2013, p.80) divide electronic interviews into synchronous and asynchronous interviews, and further into text-based and image-based audio-visual interviews. Real-time AV interviews such as Skype or video-conference interviews (Janghorban et al. 2014) are very similar in concept to the original FTF interview and were offered to participants; albeit with strengths and weaknesses particular to that technique: non-verbal cues are still present, but the visual

field is restricted to the head and face only, and thus any inferences gleaned from body-language are lost. Text-based interviews, both synchronous (such as messenger interviews (Stieger & Göritz 2006) and asynchronous interviews such as email (Hooley et al. 2012) - must, necessarily, be lacking in any non-verbal cues and as such were previously considered – at best – to be adjuncts of extensions to the FTF interview or as “poor substitutes” to the gold standard, but are nonetheless increasingly being utilised and accepted as different interview techniques in their own right (Braun & Clarke 2013, p.79).

The original project proposal had planned for FTF interviews from the outset, hence the focus in previous sections on building rapport and reciprocity in interviewing. However, during the proposal preparation stage provision for electronic interviews was also included in the project proposal in order that ethical approval would be granted for these – as the anonymity and invisibility might ameliorate any embarrassment felt by participants. Please refer to Appendices 4, 5, 6 and 7 for ethical approval documentation for the interview study. This foresight was later confirmed by the gatekeeper for the social media support group, who expressed the following opinion:

*‘Is there any scope to offer online interviews? In my experience with our support group, people are very private about HPV & quite ashamed; I’m not sure that you would get many participants with face to face interviewing alone.’*

*Gatekeeper – personal communication, Feb 2017*

The researcher reconfirmed with the gatekeeper that interviews were the most suitable data collection method, but that online interviews could be offered, as they had been approved as a data collection method in the application for ethical approval. During the research process, once contact had been made, all participants were offered a choice between face-to-face, online AV interviews (via Skype), online synchronous (messenger)

interviews or online asynchronous (email) interviews. All participants chose or requested email interviews. Both communications with the gatekeeper and with participants during the data collection process led to the reflections on insider research.

### 3.8.6. Insider Research

According to Costley et al. (2010, p.2) an insider researcher is an individual who studies an area in their own field of practice – the insider researcher occupies ‘a unique position to study a particular issue in depth and with special knowledge about that issue.’ In addition, Costley et al. also state that ‘when researchers are insiders, they draw upon the shared understandings and trust of their immediate and more removed colleagues.’ Whilst this project is not based in the researcher’s actual workplace, it does involve examination of the outcomes of the field of practice, and in this context, the colleagues to whom Costley’s team refers to include HPV positive women, other stakeholders in the NHSCSP service such as healthcare professionals and PHE, and the charitable institutions who provide support and guidance to affected individuals. Both Costley et al. (*ibid*) and Voloder & Kirpitchenko (2016, p.13) speak of the concept of ‘social situatedness’, arguing that ‘organizational, professional and personal contexts will affect the way a piece of research and development is undertaken.’

Reed and Proctor (1995, p.195) list the idealised criteria for practitioner research in health care. They define research as a social process, which should educate all participants, focusing on aspects of practice for which the researcher may initiate change. Additionally, the insider researcher in the healthcare setting should be able to identify and explore socio-political factors and expose values for critical enquiry and discussion in order to yield insights



that can be communicated to wider audiences. According to these criteria, this study can be considered a piece of insider research, as the findings will aim to initiate changes to the post-diagnosis practice, to promote experience sharing and information supply to HPV positive women on the basis of themes identified in the research. These findings aim to yield insights that can be communicated to wider audiences – such as stakeholders, other HPV-positive audiences and policy-makers such as PHE. Socio-political factors abound within the topic, as covered in the first two chapters – including the politicisation of vaccination, the change in social context brought about by the change in screening method and the gender lens currently applied to the subject of HPV.

Within the specific research context of HPV, there is a dearth of literature on the perspective of insider research. Nack (2002, 2000) took a literal approach to the concept in her studies surrounding STD stigma, relating her own issues with HPV positivity to participants in order to foster a sense of trust and reciprocity. This aspect of the research cannot be shared by this author, although there is a significant argument to be made for this research to have been undertaken by what both Dwyer & Buckle (2009) and Kerstetter (2012) call an ‘insider-outsider’ researcher – occupying ‘the space between’, from the perspective of both the researcher and the participants. The researcher is an insider as the study is situated in the field of practice – HPV diagnosis, by examining the day-to-day consequence of this diagnosis. In addition, the shared knowledge of clinical terms and acceptance into the online community (after applying to and communicating with group administrators) lent an insider perspective to the researcher. From the perspective of participants, the researcher, whilst not being HPV positive, could be considered one of Goffman’s ‘wise’ – having knowledge of the subject and the attached stigma, but who was

able to treat the participants as 'normals' (again, using Goffman's terminology). However, in terms of lived experience of HPV positivity, the researcher is definitely an outsider.

The position of insider/outsider did affect the researcher's actions and influence reflexivity. For example, once accepted (by the administrator/gatekeeper) to the social media support group, the researcher did not 'lurk' before announcing her presence as a researcher. Beaulieu & Estalella (2012) define lurking as a slang term for membership of/subscription to an online resource/forum whereby the individual reads posts rather than or prior to posting or engaging with the online community. Beaulieu (2004) cited in Tsatsou 2016, p.178) found that prolonged 'lurking' prior to announcing oneself as a researcher lead to anger and rejection by the online community, as it led to suspicions of observation/data collection without consent. Aware of this dilemma, the researcher worked with the administrator/gatekeeper who announced her addition to the sample groups straight away.

### 3.8.7. *Sensitive Topics*

Having considered and provided for the deontological ethical issues surrounding academic research, the research focus moved on to examine the specific ethical considerations regarding the ethical issues surrounding research sensitive topics, the ethics of phenomenology and the ethical issues encountered in Internet-mediated research. Elmir et al. (2011) note that the identification and definition of material that is construed as sensitive may be controversial. Lee & Renzetti (1990) contend that any topic may be construed as sensitive, and this may be true since the sensitivity of a topic may vary according to the individual. So a universal definition may not necessarily include a list of topics, but rather the emotions or responses they evoke. Elmir et al (*ibid*) conclude that a

sensitive topic is any that might have the potential to cause 'physical, psychological or emotional distress to the participant'. Sieber and Stanley (1988) extend this potential harm to the researcher or research team either through emotional distress or fatigue.

This research project asked women to recall or relate aspects of the lived experience of HPV positivity. As is demonstrated in the literature review chapter, HPV positivity is associated with anticipated, felt or enacted stigma (Chaudoir & Quinn 2015; Kosenko et al. 2012), relational issues (Kahn et al. 2005), has implications for fertility (Perino et al. 2011) and the prospect of malignant disease and death (McCurdy et al. 2011); all of which might trigger negative emotions in participants, thus prior to undertaking research, it was necessary to understand how such topics might be broached in a manner that might minimise distress to participants. Elmir et al. (*ibid*) recommend that to minimise the possibility of psychological distress, rapport should be created between interviewer and participant and that any power imbalance is similarly minimised, through the establishment of trust (Kryszczuk 2001). In addition, Elmir et al. recommend using sensitive and open questioning, the creation of a comfortable and intimate interview environment and considering the timing of interviews.

Although previously viewed as a 'poor substitute' to the FTF interview, due to the lack of non-verbal cues and/or context, the use of email interviews was thus a particularly pertinent choice as it allowed the participant to choose which of the questions they felt able to answer, at a time, place and in an environment of their choosing, thus placing the power in the interview with the participant. In addition, the use of asynchronous interviewing was helpful, as the participants were used to sitting at a keyboard and viewing a screen whilst posting about their own or reading about others' experiences, perhaps whilst within their own homes; participants were thus in an environment and context with which they were

already familiar and comfortable. Throughout this research any power imbalance was minimised by allowing the participants to choose with questions within the schedule they answered, and the timeline in which they answered them, as the method of data collection was via email (text-based, asynchronous interviews). In addition, reciprocity (as an approach to minimise power imbalances as espoused by Oakley (2005, 1998, 1990) was encouraged by allowing participants to know something about the project, the interviewer's life and professional practice.

Mann & Stewart 2002 (cited in: Gubrium & Holstein 2002, p.2) advocate the use of computer-mediated communication (CMC) in qualitative research interviews, as it allows both participants and researchers to 'read, reply, print or forward... at their leisure'. CMC may be advantageous in the collection of data surrounding sensitive topics (Elmir et al. 2011), as participants may feel uncomfortable or embarrassed about disclosing sensitive information in person; and the geographical distance, relative anonymity and invisibility of CMC (Suler 2004) may help reduce these feelings. Ison (2009) also advocates the use of email interviews in the case of individuals with disabilities that prevent the verbal communication demanded by a face-to-face interview, and notes that due to the asynchronous nature of email, that communication may be enhanced as it allows participants time to consider their response.

### **3.9. Sources of Bias**

#### *3.9.1. Interviewer Effect*

The existence of the interviewer effect has been noted across sociological and psychological literature surrounding qualitative data gathering. The interviewer effect is defined as “the distortion of response to a personal or telephone interview which results from differential reactions to the social style and personality of interviewers or to their presentation of particular questions” (Himelein, 2015; Catania et al. 1996; Kane & Macaulay 1993; Cotter et al. 1982). This may manifest as social desirability bias whereby respondents give answers that portray them in the best light possible rather than the answers that are the most accurate reflection of actual behaviours (van de Mortel 2008; Holbrook et al. 2003; Presser & Stinson 1998; Nederhof, 1985) – the issues surrounding social desirability bias will be covered in the next section.

The fact of the interviewer effect may be important in the case of stigmatised diseases, such as HPV or cervical cancer; however, very little literature exists on the subject of the interviewer effect in relation to HPV. The closest analogues are the interviewer effect in research surrounding HIV positivity (as a stigmatised disease), and research on the reporting of intravenous drug behaviours (as stigmatised behaviours); where several studies demonstrate that participation bias and mode of interview may affect reporting of drug and alcohol use and sexual behaviours (Aquilino, 1994; Catania et al., 1990). Newman et al. (2002) invited individuals subscribing to a needle exchange programme to participate in interviews that administered a questionnaire. Respondents were randomly assigned to one of two conditions – a face-to-face interview or a computer-assisted self-interview. The questionnaire had three overall sections – “stigmatised behaviours”, “neutral behaviours”

and “psychological distress”. Newman found that individuals in the computer-assisted self-interview condition reported stigmatised behaviours more often, and that individuals in the face-to-face interview condition reported psychological distress more often, indicating that the relative anonymity and invisibility offered by computer based interviewing increased truthfulness (validity) in reporting whilst minimising distress. Additionally, Perlis et al. 2003 conducted a similar study that randomly assigned injecting drug-users to one of two interviewing conditions (either an assisted personal interview or a computer-assisted self-interview). The computer-assisted self-interview was associated with greater reporting of potentially stigmatised drug, sex or HIV behaviours. Moreover, 41% of the computer-assisted self-interview group indicated that they would prefer all further interviews to be carried out in this manner. These findings are in accord with Davis *et al* (2009) who noted that interviewer effects may be particularly operant within public health surveys where respondents are “likely to be queried about racial attitudes, sensitive behaviours or other topics prone to socially desirable responding.” Therefore, by using asynchronous electronic interviews, the researcher effectively minimised her presence as an interviewer, potentially maximising the validity of data obtained, whilst hypothetically minimising the psychological distress entailed in the interview process.

### 3.9.2. *Social Desirability Bias*

According to van der Mortel, social desirability bias (SDB) arises through either self-deception or other-deception (van der Mortel, 2008). SDB arises from the individual’s need to construct a favourable image of themselves in the eyes of others (Goffman 1990b, p.19). Research has found differences in social desirability bias according to the mode of

survey/interview employed to collect data. Holbrook et al. (2003) found that in a review of surveys comparing FTF interviews with random-digit dialling (RRD) telephone interviews, individuals responding via telephone were more likely to satisfy the interviewer – responding to questions using minimal engagement, such as no-opinion responses or acquiescence – (Krosnick 2000), were less engaged and less co-operative. Holbrook et al. also found that telephone participants took less time to complete the survey/interview but were more dissatisfied with the interview length, were more suspicious of the interviewer and more likely to engage in socially desirable responses. Holbrook’s team identify several reasons for the lack of engagement among telephone interview participants: interview pace – interview via telephone may result in the participant wishing to get off the phone as quickly as possible to get on with their day; rapport – telephone interviews may not allow the establishment of trust and rapport among the interviewer and participant in the same way as FTF interviews, since a major factor in the establishment of rapport is the sharing or mimicking of non-verbal behaviours or cues (Drolet & Morris 2000).

Electronic asynchronous interviews might be prey to all of the factors and pitfalls described above for telephone interviews, but there are important differences in the recruitment process of these individuals that might mitigate some of these factors. Firstly, unlike FTF random street surveys or RRD telephone interviews, the participants in the study were recruited from a group of like individuals, emotionally invested in the topic (Sundar 2015, p.264). Moreover, the use of asynchronicity removed the time pressure factor which featured in satisficing theory propounded by Krosnick (2000). Rapport is more difficult to establish, but the researcher represented the position of one of ‘the wise’ in Goffman’s model of stigma, and thus understood and was sympathetic to the common feature of the

group; and in addition, in demonstrating a willingness to share some information about her life encouraged reciprocity among participants.

### **3.10. Axiology – Value-Free vs. Value-Laden Research**

In tandem with the long-standing divide between quantitative/positivist and qualitative/interpretivist research, there has long been debate surrounding value-free versus value-laden research. The German sociologist Max Weber first voiced the argument that sociological research should be and remain value-free (Cooke & Philpin 2008, p.197). As this study is situated within sociology it is reasonable to ask whether this research is value-free, or value-laden. Within sociology, the definition of values pertains to the personal values held within a community or group, and whether and how these values may change under particular conditions (Cooke & Philpin, *ibid*) As this research forms part of a doctoral qualification in professional practice, the values of that profession as espoused by the researcher's employer (CARE: Compassion, Accountability, Respect and Engagement' – KGH, 2016), statutory body (the Health Care Professions Council: Transparency, Collaboration and Responsiveness – HCPC, 2016) and regulatory body (the Institute of Biomedical Science : Integrity, Professionalism and Respect); cannot be separated from the research that inspired them. However, in addition to the values of the researcher, the values of the sample population have to be considered, which may include valuing rights to privacy or non-engagement – and on the basis of all the researcher values described above, these values would have to be respected. Moreover, the study is motivated by and concerned with mitigating the social and psychological impact of a stigmatised disease, which embodies a change in the perception of an individual according to societal values – such as the social



exclusion of the stigmatised, (Becker & Arnold 1986). By being motivated to change these societal values, the research cannot be value-free.

### ***3.11. Summary of Methodology Chapter***

This chapter has examined the ontological and epistemological approaches espoused by different research philosophies and the theoretical assumptions they demand in order to demonstrate that the research philosophy of constructionism was the best fit for the research questions. Following on from the philosophical and theoretical arguments, the philosophical underpinnings of the research approach of phenomenology were elucidated – with particular reference to Svenaeus’ writings on the phenomenology of illness. The chapter also examined the advantages and disadvantages of the chosen research design (mixed methods, follow-up explanations model), discussed the stance of the research being value-laden (as opposed to value-free). The chapter closed with an examination of the chosen data collection method for the qualitative portion of the study, namely exploring the various types of qualitative research interview (in particular electronic interviews) and discussed the possible sources of bias that might arise during the qualitative data collection process.

## **Chapter Four – Quantitative Data**

### **Study 1: Questionnaire Study Exploring a Population of HPV-Focused Online Support Users**

#### **4.1. Introduction**

In order to answer the research questions given in Chapter 1, this mixed methods research project was organised using the follow-up explanations model, and was comprised of two studies. Study 1 sought to explore the characteristics of a group of women who subscribed to and used online support groups focused on living with HPV and/or cervical cancer, and gathered quantitative data using a questionnaire, administered via SurveyMonkey™. This questionnaire was delivered to women subscribing to HPV-related online support groups. The questionnaire development process, identification and recruitment of sample populations and the results of data analysis and discussion make up the body of this chapter. Study 2 was composed of a series of electronic interviews delivered via email. The development of the questions and interview schedule, identification and recruitment of sample populations and qualitative data analysis and discussion for Study 2 make up the body of Chapter 5.

Chapter 1 made the case for the comparative prevalence of HPV in the general population under HPV primary screening against the current incidence of cervical intraepithelial neoplasia, underlining the predicted increase in women being diagnosed positive for high-risk HPV; demonstrating that there will be a cohort of women with a diagnosis of HPV, who may not demonstrate neoplastic changes to the cervical epithelium (CIN) that warrant treatment. Chapter 2 examined literature on stigma, demonstrating that the stigma associated with HPV has negative psychological and sociological impacts – women being diagnosed with HPV reporting feelings of anxiety, shame and stigma (Jeynes et al.

2009; Waller et al. 2007); and also that access to social support can reduce these effects (Loane & D'Alessandro 2013). Chapter 2 also made the case for persistent high-risk HPV positivity as a case of biographical disruption, not in terms of physical disease or illness, but in terms of the effects of HPV as a stigmatised condition on access to social support as a 'mobilisation of resources' (Bury, 1982); and in terms of the anxiety and uncertainty of a liminal state in which 'neither health is confirmed nor disease excluded' (Forss et al. 2004). Chapter 2 also examined the role of online social support and its application in the case of stigmatising conditions.

Chapter 3 discussed the research philosophy underpinning the study, and the ontological and epistemological assumptions informing the theoretical perspectives of the research and the philosophers whose work influenced the chosen research approach of phenomenology and the ethical issues that might be encountered. Chapter 4 will describe the process of developing the instrument and for gathering and reporting data for Study 1 – the quantitative study, the aims for which are given below.

#### *4.1.1 Aims of the Questionnaire Study*

The overarching aims of the study are given in Chapter 1 – the research aims to explore the lived experiences of women currently or previously diagnosed with HPV, to examine the ways in which they interact with online support. Within the context of these aims, the questionnaire study intended to examine the demographic characteristics of women subscribing to HPV-related online support. The aims of the questionnaire study are summarised as follows:

- 1) To examine the characteristics of a population of users of HPV-related online support in terms of demography, HPV awareness, screening and treatment history and reported scores for perceived stress and social support.
- 2) To explore the reasons women use HPV-related online support in terms of emotional support, exchanging information, helping others or sharing experiences.
- 3) To explore the outcomes of HPV-related online support in terms of women feeling better informed about HPV, or in gaining better acceptance of HPV.
- 4) To explore women's current feelings of anxiety and/or embarrassment regarding HPV positivity (whether hypothetical or actual) and the reasons for this.
- 5) To explore the relationship between perceived availability of and satisfaction with social support and opinions regarding disclosure.
- 6) To explore the relationship between perceived availability of and satisfaction with social support, and the reasons for and outcomes of HPV-related online support use (as given in 3 and 4)
- 7) To explore the relationship between perceived stress and the reasons for and outcomes of HPV-related online support use (as given in 3 and 4).

#### *4.1.2. Research Questions*

The research questions for this study draw on the main research questions set out in Chapter 1 and are informed by the literature examined in Chapter 2, specifically investigating the possibility of HPV as a biographical disruption by exploring the reasons for anxiety over

HPV positivity; and through examining the possible benefits women may gain from using online support. The research questions for the questionnaire study are given below:

- 1) What are the demographic characteristics of a group of online support users?
- 2) Is there a relationship between perceived social support and disclosure of HPV positivity – do women who indicate their agreement with disclosure report higher social support?
- 3) Are the reasons for HPV-related online support use (for emotional support, exchanging information, helping others or sharing experiences) associated with increased perceived availability of and satisfaction with social support?
- 4) Are the outcomes of HPV-related online support use (being better informed about HPV and better acceptance of HPV) associated with reduced perceived stress?

#### *4.1.3. Hypotheses*

Based on the literature reviewed in Chapter 2 and the research aims and questions above, the following experimental hypotheses are put forward.

H<sub>e</sub>1: The data will show a significant relationship between reported intent to disclose HPV positivity and increased scores for the availability of and satisfaction with social support. Linear regression will be performed to test whether increased social support scores predict agreement with disclosing HPV positivity.

H<sub>o</sub>1: There will be no significant relationship between social support scores and disclosure intention.

H<sub>2</sub>: The data will show a significant relationship between a reported lack of anxiety over HPV positivity and increased scores for availability of and satisfaction with social support. Analysis of variance will be performed to examine whether the differences in social support scores and perceived stress scores between 'Anxious' and 'Not Anxious' participants are significant.

H<sub>02</sub>: There will be no significant relationship between social support and/or perceived stress and anxiety over HPV positivity.

H<sub>3</sub>: That agreement with the uses of online support for emotional support, exchange information, to help others and to share experiences will be significantly associated with increased scores for social support, and with reduced scores for perceived stress. A multivariate general linear model will be used to examine whether agreement with reasons for online support use (for emotional support, exchanging information, helping others or sharing experiences) is associated with increased scores for social support and reduced scores for perceived stress.

H<sub>03</sub>: There will be no significant relationship between uses of online support and scores for social support and perceived stress.

H<sub>4</sub>: That agreement with the outcomes of online support use to feel better informed about HPV, and to gain better acceptance of HPV will be significantly associated with increased scores for social support, and with reduced scores for perceived stress. A multivariate general linear model will be used to examine whether agreement with outcomes of online support use (feeling better informed about HPV, and gaining better acceptance of HPV) is associated with increased scores for social support and reduced scores for perceived stress.

H<sub>0</sub>4: There will be no significant relationship between outcomes of online support use and scores for social support and perceived stress.

#### **4.2. *Methods: Questionnaire Design***

The research instrument took the form of a survey, administered as a questionnaire. The questionnaire was designed to allow both quantitative analysis, through the use of closed-ended, multiple-choice questions; and limited qualitative analysis through the use of free text entry questions. Ethical approval was sought from and granted by De Montfort University (please refer to Appendix 1). The questionnaire was created and administered using SurveyMonkey™. Sites that might attract appropriate respondents were approached and the project proposal, ethical approval, a document containing the questionnaire text and links to the live questionnaire were submitted for consideration. The sample populations identified are described in section 4.3. The questionnaire was composed of five sections – demographic information, cervical screening and HPV testing history, participants' use of the internet and social media, a social support questionnaire and a perceived stress scale. These sections are discussed in more depth below. A copy of the questionnaire text can be found in Appendix 2.

##### **4.2.1. *Demographics***

The first section of the questionnaire was designed to explore the demographic characteristics of women who subscribe to online resources devoted to HPV positivity, abnormal cervical screening results or colposcopic examinations and groups devoted to

cervical cancer. Respondents were requested to indicate their age according to age brackets. The age range of the instrument was 18 to 64 years of age, chosen to include women who had been vaccinated (>18 years) or diagnosed outside of the programme and at the upper end to include women still receiving follow-up for treated CIN. Relationship status was chosen as a demographic as studies show that older women and women in established relationships have lower anxiety about HPV positivity and disclosure than younger or single women (Kwan et al. 2011; Newton & McCabe 2008a; Newton & McCabe 2008b; Filiberti et al. 1993). In addition, women who do not foster close personal relationships (such as those that might arise through co-habitation) are more likely to resort to online support (Horgan et al. 2013; Eastin & Larose 2005). Additionally, respondents were requested to identify themselves by ethnic group in order to examine whether or not use of online support reflects the overall ethnic proportions reflected in cervical cancer incidence as reported by Cancer Research UK.

#### *4.2.2. Cytology Screening & HPV Testing History; Knowledge of HPV*

The second section of the questionnaire examined respondents' cytology screening and HPV testing history; to explore awareness of HPV within the population and to examine for whom the topic had been researched – for themselves or on behalf of others. In addition, relative stage within the diagnostic and treatment arc was reported in order to investigate at which point women had recruited online assistance and the duration of their memberships. Awareness of HPV was a single-item question, with two response options ('Yes'/'No'). HPV testing and cervical screening history questions each contained multiple response options. Response options for HPV testing included different options



for 'No' (such as 'I have not been invited yet' – to accommodate women under 25 years of age – and 'I choose not to participate'). Response options for screening history included different categories to accommodate the different stages of the diagnostic and treatment arc (such as 'I have an appointment but have not attended yet', 'I have had a biopsy', 'I have had treatment').

Originally, a 6-item measure of HPV knowledge was included in order to compare women's knowledge of HPV against perceived stress, to examine whether increased knowledge of HPV reduced or increased perceived stress. The HPV knowledge score results are not included here as an outcome, as validated HPV knowledge measures were published shortly after the questionnaire was released (Waller et al. 2013). A frequency analysis of responses to individual questions from this 6-item measure is included to examine potential knowledge gaps in the sample. Knowledge statements included 'HPV is a sexually transmitted infection', 'HPV is the most common STI in the UK', 'HPV may go away by itself (self-resolve)', 'HPV may not be stopped by condoms', 'HPV may not cause any outward signs' and 'HPV may cause cervical cancer'. All of the statements included in the instrument were true – no untrue statements or 'distracters' were included. In addition, participants were asked to select which items they believed to be true, as opposed being offered a 'true/false' option. Therefore missing responses do not necessarily indicate that women believed unselected statements to be false.

#### *4.2.3. Anxiety & Embarrassment Over HPV-Positivity; Reasons for Anxiety*

Measures for this section of the instrument examined women's anxiety and women's embarrassment about an actual or hypothetical HPV-positive test result. For anxiety, women were asked to rate their level of anxiety on a five point Likert scale from

'Extremely anxious' to 'Not at all anxious'. Similarly, women were asked to rate their embarrassment about an actual or hypothetical HPV-positive test result on a five point Likert scale from 'Extremely embarrassed' to 'Not at all embarrassed'. These questions were included as studies by (Kim 2012; McCaffery et al. 2010; Waller et al. 2009; Waller et al. 2007; McCaffery et al. 2004) variously report from face-to-face interviews that women feel shame and anxiety over testing HPV positive. Additionally, women were asked to select reasons for their anxiety over HPV-positivity. There were seven response categories: 'Disclosure – I am anxious about telling my partner, family or friends', 'Fertility – I am anxious that HPV might affect my ability to have children', 'Health – I am worried about developing cancer', 'Health – I am worried about cancer returning', 'Life – I am worried about dying', 'None of the above – I am not concerned' and a free text box in which participants could enter other reasons that did not fit into the responses given above. Women could select multiple responses. These response categories reflected the major themes in literature identified in Chapter 2 – namely stigma (Daley et al. 2010; Brown et al. 2007; Newton & McCabe 2005; Nack 2002); disclosure (Harvey-Knowles & Kosenko 2012; Kosenko et al. 2012; Perrin et al. 2006) and themes identified in literature examining women's most salient information needs and messages associated with HPV. These included associations with cancer development and mortality (Hendry et al. 2016; León-Maldonado et al. 2016; Lee Mortensen & Adeler 2010) and questions surrounding fertility (Souho et al. 2015).

#### *4.2.4. Use of the Internet and Social Media for Social Support*

Section 3 comprised questions regarding respondents' use of the Internet. This section of the questionnaire asked how long participants had been using the Internet, and for an approximation of the frequency of use (as sessions per day). The rationale behind asking these questions was to explore whether an association existed between Internet use and perception of social support. In addition, this section used questions formulated by Beaudoin and Tao (2007) in their study examining the empowering effect of online support groups among cancer patients. Four of their questions specifically explored the reasons participants used online support groups and online healthcare information gathering – by asking participants to indicate agreement with statements about using online support for: emotional support, exchanging information, helping others or sharing experiences. Four questions examining reasons for online support use were thus included, in the questionnaire asking participants to indicate their agreement on a 5 point Likert with using online support for these reasons – emotional support, exchanging information, helping others and sharing experiences. The final two questions examined the possible outcomes of HPV-related online support use using 5 point Likert scale of agreement/disagreement with statements about: being better informed about HPV and gaining better acceptance of HPV.

#### *4.2.5. Measurement of Social Support*

Section 4 consisted of a short form of the Social Support Questionnaire (SSQ). The SSQ was introduced by Sarason et al. (1983) as a means of assessing social support by examining the availability of social support and the participant's satisfaction with the

available support. The original SSQ contains 27 items, takes around 15 minutes to complete and shows good test-retest reliability (Sarason et al. 1987). Two short forms of the questionnaire exist – a 3-item version (SSQ3) and a 6-item version (SSQ6). To reduce attrition rates associated with lengthy questionnaires (Rolstad et al. 2011) the 6-item version, SSQ6 was used in this study. SSQ6 also shows good internal validity and test-retest reliability (Rascle et al. 2005) and has been used in the examination of social support among breast cancer patients (Boinon et al. 2014) and gynaecological cancer patients (Torkzahrani et al. 2013).

#### *4.2.6. Measurement of Perceived Stress*

Section 5 of the research instrument consisted of a short form of the Perceived Stress Scale [PSS]. The original PSS is a 14-item instrument developed by Cohen et al. (1983) to provide a reliable measure of volunteers' perceptions of the level of stress they were currently undergoing. A shorter 10-item instrument was introduced by Cohen & Williamson (1988), which has since undergone further reliability and validity testing (Nordin & Nordin 2013; Lee 2012; Roberti et al. 2006). Since it was introduced, both the PSS and PSS-10 have been used to measure individuals' perceived stress following a cancer diagnosis, including breast cancer and mastectomy (Golden-Kreutz et al. 2005, 2004) and in the relationship between stress and immunity in breast cancer recovery (Thornton et al. 2007). The PSS-10 has also been used in tandem with the SSQ in studies examining the management of anxiety (Panayiotou & Karekla 2013). Beaudoin & Tao (2008) used the PSS in modelling the impact online cancer resources in cancer patients' supporters, finding that self-perception of life stress reduced proportionally with the

length of time volunteers were using online support groups. Cassidy (2013) employed the PSS-10 in examining perceptions of stress in female cancer caregivers recruited via online support groups. The PSS-10 was thus chosen as means of measuring perceived stress for this study as it has been repeatedly tested for validity and reliability, has been used with populations of individuals either suffering from or supporting others with cancer, and has been used with populations recruited through online sources.

#### *4.2.7. Development of the Questionnaire*

The development of the final questionnaire was an iterative process. For the main body of the questionnaire, many of the items were derived from instruments used in previous studies analogous to the current research with a good track record of citations or which have been proved by other methods such as national statistics (the demographic section, which is derived from the UK Census). This decision was made in order to maintain the academic validity of the instrument as far as possible, without introducing researcher bias. Section 2 of the questionnaire was the section which contained the most original questions and responses. As previously described, these questions explored volunteers' screening and HPV testing history. In order to minimise researcher bias and possible psychological harm to volunteers (by introducing anxiety), these questions were developed by the author, with the reference to the HPV Triage and Test of Cure algorithms (PHE 2016) and NHSCSP documentation (NHSCSP 2016) and the local screening policy. These questions were then examined by a 'working group' at Kettering General Hospital (the author's workplace) at the request of the author. The working group comprised of the Advanced Practitioner (AP) and Cervical Screening Lead, the Consultant

Pathologist specialising in gynaecological malignancy, a Consultant Gynaecologist and the Lead Nurse Colposcopist.

The questionnaire was then examined by Professor Lixian Jin of De Montfort University, an academic specialising in questionnaire design. Professor Jin made some recommendations to the structure of the questions (for example the use of age categories instead of entering age as a set of digits; and the questions used to identify the independent variables as set out in the aims and objectives). The recommended amendments were made. The questionnaire document is available in Appendix 2.

#### **4.3 Sample Populations**

In order to locate appropriate and relevant populations – online support or social media groups of women – searches were carried using internet search engines including Google, Bing and Yahoo!. Another search was carried out using the search facilities of social media platforms. Facebook, Mumsnet, Twitter, Instagram, Gaia Online and Reddit were all searched for appropriate support groups. The search terms used for both types of search engine (Internet and social media) are given in Table 4.1., and the participant groups identified are described in the following paragraphs.

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**Search terms utilised to identify possible sources of participants**

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Abnormal smears  
Abnormal colposcopy  
Cervical cancer support  
Cervical cancer minority ethnic population  
Colposcopy support  
HPV awareness  
HPV support  
HPV minority ethnic population  
STD/STI support

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*Table 4.1: Terms used in the identification of participant populations*

#### *4.3.1. The Teal Ladies*

The 'Cervical Cancer Awareness' Facebook page, also known as 'The Teal Ladies' is an online not-for-profit peer support group run by cancer survivors for sufferers and survivors of female genital tract (FGT) cancers. Although individuals with HPV positivity and/or cervical cancer are both supported, the group is not specific to either condition, as it additionally provides peer support to women with endometrial and ovarian cancers. The page and group was set up in December 2009; at the time of writing, the group had 3,515 members with large member bases in the United Kingdom, the US, Canada and Australia. The group does not purport to give expert help, clinical advice or liaison but is run purely for the purposes of emotional support. The majority of individuals posting in the group do so to 'diarise' their experiences or to ask for reassurance or informal advice on their symptoms from peer patients. Respondents from this group were recruited from the UK branch of the group.

#### *4.3.2. Jo's Cervical Cancer Trust*

Jo's Cervical Cancer Trust is a UK charity dedicated to supporting women affected by cervical cancer. The charity was founded as a trust in 1999 by James Maxwell, following the death of his wife from cervical cancer in the same year. The trust was incorporated as a charity in 2010. According to the mission statement on its website, the charity aims to reduce the impact of cervical cancer on the lives of sufferers and their families. Through its website and associated Facebook page and Twitter feed the group organises fundraising, provides support via an online forum and access to clinical advice and gives information regarding the diagnosis and treatment process and follow-up. In addition, Jo's Trust also hosts research pages to recruit volunteers to studies exploring the field of cervical cancer.

#### *4.3.3. BME Cancer Voice*

BME Cancer Voice is a UK organisation based in Leeds which aims to provide informal support and advice to British Minority Ethnic individuals. BME Cancer Voice is not specifically dedicated to the support of HPV sufferers or cancers of the female genital tract, but supports BME patients of all cancers. The group was originally developed and run by the National Cancer Action Team until this was abolished in 2013 under NHS reforms. BME Cancer Voice aims to increase the cultural competence of the NHS in the treatment of cancer patients from British Minority Ethnic groups by identifying cultural, spiritual and religious needs specific to BME cancer patients in order to identify solutions for improved experiences. The working group was originally implemented as a result of surveys of cancer patient experiences run annually by the Department of Health. The results of surveys indicated that patients of BME backgrounds had poorer experiences of using NHS cancer

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services than white patients living within the same health authority (Independent Cancer Taskforce 2015). These experiences included lack of appropriate interpreters, information in relevant languages and in cases where post-operative prostheses were required, a lack of prosthetics in skin tone appropriate colours for ethnic populations.

#### **4.4. Response Rate**

Following identification of and approaches to sample populations (described previously) the questionnaire was posted on the research pages of Jo's Cervical Cancer Trust and the Facebook pages of the Teal Ladies and BME Cancer Voice. The questionnaire was available on SurveyMonkey for six months from December 2014 to June 2015. According to their annual report, Jo's Trust received 320,000 'clicks' in 2016-2017 (Jo's Cervical Cancer Trust 2017) resulting in over 2.5m web sessions, however no data is given to the amount of traffic any specific area of the website receives (in this case, the 'Research' pages, where the advert for the research project was hosted). The Teal Ladies Facebook group has approximately 3,500 members of whom 1,200 are based in the UK. BME Cancer Voice has approximately 300 members on social media. Of this combined audience, 111 responses were received – of these 4 responses had no data, leaving 107 respondents. Of the 107 respondents, 81 respondents responded to every question. Data was missing for a question on HPV awareness (N = 26), the social support questionnaire (N = 21)) and the perceived stress scale (N = 26). The small sample size is accepted as a limitation to the study.

#### **4.5. Data Analysis**

Data were gathered via SurveyMonkey™ and exported into SPSS. Descriptive statistics were utilised to examine the modal age ranges, employment, ethnicity and relationship status of respondents. Cross-tabulations were employed to examine groupings for diagnostic/treatment stage and duration of membership to online support groups, and between diagnostic/treatment stage and perceived stress and also perceived social support. Tables comparing mean scores for social support and perceived stress were used to explore whether possible relationships existed between the independent (questionnaire) variables and the dependent variables, and inferential statistics were used to examine the significance of these relationships. Linear regression was utilised to test the first experimental hypothesis; exploring possible associations between perceived social support and disclosure intention. Analysis of variance was used to test the second experimental hypothesis – examining the relationship between increased scores for social support in women reporting a lack of anxiety over HPV positivity. The third and fourth experimental hypotheses were tested using multivariate generalised linear modelling to explore the significance of differences between mean scores for perceived social support and the reported reasons for online support use (exchanging information, helping others, sharing experiences and emotional support), and between mean scores for perceived stress and the reported outcomes of online support use (improved acceptance of HPV, improved knowledge of HPV). The results of analyses are given on the following pages.

## 4.6. Results of Quantitative Data Analysis

### 4.6.1. Population Demographics

Demographic Characteristic		
Age Bracket	N	Percent
18-24	6	5.4%
25-34	39	36.0%
35-44	36	33.3%
45-54	20	19.8%
55-64	5	4.5%
65-74	1	0.9%
Total	107	100
<i>Relationship Status</i>		
Married/Civil Union/Co-Habiting	84	78.4%
Divorced/Separated	11	9.9%
Single	11	9.9%
Prefer Not to Say	1	0.9%
Total	107	100
<i>Ethnicity</i>		
White British	104	97.3%
White Irish	1	0.9%
Black Caribbean	1	0.9%
Bangladeshi	1	0.9%
Total	107	100
<i>Employment Status</i>		
Employed, working 40+ hours per week	32	29.0%
Employed, working 1-39 hours per week	38	34.2%
Not employed, looking for work	10	9.0%
Not employed, not looking for work	15	13.5%
Retired	1	0.9%
Disabled, not able to work	10	9.0%
Prefer not to say	1	0.9%
Total	107	100

Table 4.2: Demographic characteristics of HPV online support subscribers

The modal age bracket was 25-34 years (36%, N = 39), with the majority of women reporting being in a relationship (78.4%, N = 84) and the overall majority women reporting being White British (N = 104, 97.1%) and working 1-39 hours per week.

#### 4.6.2. Cervical Screening Frequency/History

This section of the research instrument asked women to report their cervical screening frequency, knowledge and cervical screening history, to explore the cervical screening profiles of women who subscribed to HPV-/cervical cancer-related online support. Cervical screening history and frequency were explored to discover the number of women who had been diagnosed outside of the screening programme (prior to first call) and what portion of the sample population were on follow-up for a previous abnormality. Women indicated their cervical screening history as follows:

Cervical Screening History		
Have you ever had an abnormal smear		
An abnormal result is any of the following: 'Borderline', 'Mild', 'Moderate', 'Severe', '?Invasive disease', '?Glandular neoplasia'		
	N	Percent
No, I have never been screened	2	1.8%
No, I have never had an abnormal result	9	8.6%
Yes, I have had an abnormal result	96	89.7%
Missing Data	Nil	
<b>Total</b>	<b>107</b>	

*Table 4.3: Distribution of respondents by cervical screening history*

Cervical screening frequency was explored by asking women to select from response categories: 'Never' for women who have never been screened because they choose not to participate or due to being too young for screening; 'Occasionally', 'Regularly', 'Frequently' (women who opt for additional private screening) and 'Frequently' (due to being on followed

up for previous treatment). These data were cross-tabulated with the abnormal screening history responses, and are given in table 4.4.

How often do you participate in cervical screening	Have you ever had an abnormal smear			Total
	No, never screened	No abnormal result	Yes, I have had an abnormal result	
Never, I choose not to participate	0	0	1	1
Never, I have not been invited yet	2	0	5	7
Occasionally, I don't always go when invited	0	1	7	8
Regularly, when invited	0	5	16	21
Frequently, I arrange for additional screens	0	1	6	7
Frequently, being managed post-treatment	0	2	60	62
Prefer not to say	0	0	1	1
Total	2	9	96	107

*Table 4.4: Cross-tabulation of abnormal smear history and cervical screening frequency*

The majority of respondents had had an abnormal result (N = 96, 89.7%) and of these, 60 were being managed post treatment. Women were also asked to report the stage of the screening/treatment process they were at.

Treatment History	N	Percent
Appointment, not attended yet	2	1.8%
Offered an appointment, had a biopsy	29	26.1%
I have had treatment	39	35.1%
Have had treatment and follow-up	27	24.3%
Not had treatment	2	1.8%
Not needed treatment	8	7.2%
Missing Data	Nil	
Total		

*Table 4.5: Distribution of respondents by treatment history*

The majority of women (61.2%) described being at either the biopsy (N = 29, 26.1%) or treatment stage (N = 39, 35.1%). Responses to screening frequency were cross-tabulated with treatment stage to further describe the population. The distribution of responses is given in Table 4.6.

		Have you ever been offered treatment for an abnormal smear					Total	
		No treatment yet	Biopsy	Treatment	Treatment and Follow-Up	Not had treatment		Not needed treatment
Screening Frequency	Choose not to participate	0	1	0	0	0	0	1
	Not invited yet	0	3	2	0	1	1	7
	Occasionally	1	3	2	1	0	1	8
	Regularly	0	6	4	5	1	5	21
	Frequently, Additional screens	1	2	2	1	0	1	7
	Frequently managed post treatment	0	13	29	20	0	0	62
	Prefer not to say	0	1	0	0	0	0	1
	Total	2	29	39	27	2	8	107

*Table 4.6: Cross-tabulation of screening frequency and treatment stage responses*

Results for the demographic and screening history will be further examined in the discussion section.

#### 4.6.3. Awareness of HPV, HPV Testing History

Women who subscribed to HPV/cervical cancer related online support were asked to indicate their awareness of HPV, in order to examine what proportion of such a population were aware of the existence of the virus. Responses to the question ‘Are you aware of the Human Papillomavirus (HPV)?’ and the follow-up question ‘Do you have daughters eligible for the HPV vaccine?’ are given in Table 4.7.

HPV Awareness	Number	Percentage
Are you aware of the human papillomavirus (HPV)?		
Yes	79	73.8%
No	2	1.8%
Missing data	26	24.2%
Do you have daughter(s) eligible for the HPV vaccine?		
Yes	29	27.1%
No	77	72%
Prefer not to say	1	0.9%
Missing data	Nil	

*Table 4.7: Awareness of HPV*

The HPV awareness question was the first instance of missing data so far in the questionnaire. Responses to these questions and possible reasons for missing data will be examined in the discussion section. In addition to awareness, women were asked to indicate whether or not they had had an HPV test. Responses are given in Table 4.8.

HPV Testing History		
Do you know if you have ever had an HPV test?	Number	Percentage
No, I am not in the screening programme (not invited yet)	5	4.6
No, I choose not to participate in the screening programme	1	0.9
No, I have not been HPV tested	16	14.9
I don't know	10	9.3
Yes, I have had an HPV test	75	70.0
Total	107	100

*Table 4.8: Distribution of population by HPV testing history*

HPV testing history was cross-tabulated with cervical screening frequency to explore distributions within response categories. It was clear that the majority of respondents who had had an HPV test (N = 75) were being followed up post-treatment (N = 48). Cross-tabulation of HPV testing history and cervical screening frequency are given in Table 4.9.

		HPV Testing Status			Total		
		No, not invited yet	No, choose not to participate	No, not HPV tested		I don't know	Yes, I have had an HPV test
How often do you participate in cervical screening?	Never I choose not to participate	0	0	0	1	0	1
	Never, I have not been invited yet	4	0	1	1	3	7
	Occasionally, I don't always go when invited	0	0	1	3	4	8
	Regularly, when invited	0	0	4	1	14	21
	Frequently, I arrange additional screening	0	0	1	0	6	7
	Frequently, I am being managed post-treatment	1	1	9	3	48	62
	Prefer not to say	0	0	0	1	0	1
Total	5	1	16	10	75	107	

*Table 4.9: Cross-tabulation of HPV testing history and cervical screening frequency*

In addition to awareness of HPV and HPV testing history, women were presented with six knowledge statements about HPV, and asked to select which of these statements they believed to be true. A frequency table of responses is given below. Where reported, N indicates the number of women who selected the statement as true.

HPV Knowledge Statements	Number	Percent	Missing	Percent
HPV is a sexually transmitted infection	87	81.4%	20	18.6%
HPV is the most common STI in the UK	46	42.9%	61	57.0%
HPV may go away by itself (self-resolve)	66	61.7%	41	38.3%
HPV may not be stopped by condoms	53	49.5%	54	50.4%
HPV may not cause any outward signs	90	84.1%	17	15.8%
HPV may cause cervical cancer	106	99.1%	1	0.9%

*Table 4.10: Frequency table of knowledge statements for HPV*



#### 4.6.4. Social Support and Perceived Stress Scores

Perceived availability of and satisfaction with social support were measured using Sarason's SSQ-6 (Rasclle et al. 2005; Sarason et al. 1983). Perceived stress was measured using Cohen's PSS-10 (Cohen & Williamson, 1988). Scores for all respondents are given in the table below.

Measure	N	Minimum	Maximum	Mean	Std. Deviation
SSQN	86	0.0	4.8	2.1	1.0
SSQN	86	1.0	5.0	4.2	0.9
PSS	83	17.0	28.0	20.9	2.5

*Table 4.11: Descriptive statistics of all scores for social support and perceived stress*

Scores for availability of social support (SSQN) were given by 86 respondents, and ranged from 0.0 to 4.8, with a mean score for the whole group of 2.1 (SD = 1.0). Scores for satisfaction with social support (SSQS) were also given by 86 respondents and ranged from 1.0 to 5.0, with a mean score for the whole group of 4.18 (SD = 0.9). Scores for perceived stress were completed by 83 respondents and ranged from 17.0 to 28.0 with a whole group mean of 20.9 (SD = 2.5).

#### 4.6.5. Disclosure Intention and Preferred Confidant Group

Women were asked to indicate whether or not they would confide in anyone regarding a positive HPV result. The question was a three item response: "Yes, "No" or "Prefer not to say". There were no missing data for this question. Responses are given in Table 4.12.

HPV Positivity Disclosure Intention		
Would you confide in anyone about a positive HPV result	Number	Percentage
Yes	94	87.9
No	12	11.2
Prefer not to say	1	0.9
<b>Total</b>	<b>107</b>	<b>100.0</b>

Table 4.12: Distribution of respondents by disclosure intention

Women were grouped by their opinions on disclosure, and mean scores for social support availability (SSQN), social support satisfaction (SSQS) and perceived stress were compared in Table 4.13.

Would you confide in anyone about a positive HPV result?				
		SSQN	SSQS	PSS
Yes	Mean	1.79	3.94	20.96
	N	94	94	75
	Std. Deviation	1.24	1.06	2.37
No	Mean	1.24	3.57	20.29
	N	12	12	7
	Std. Deviation	1.16	1.07	3.68
Prefer not to say	Mean	1.00	2.83	20.00
	N	1	1	1
	Std. Deviation	.	.	.

Table 4.13: Mean scores for SSQN, SSQS and PSS by disclosure intention group

Women who stated that they had or would disclose their HPV positive status demonstrated higher mean scores for both availability of and satisfaction with social support, but also higher mean scores for perceived stress. In order to examine the first experimental hypothesis  $H_{E1}$  – stating that a significant relationship exists between increased scores for availability of and satisfaction with social support and intent to disclose HPV positivity, linear regression was performed to examine whether a relationship existed between perceived stress and/or social support and disclosure intention. When disclosure intention was predicted it was found that perceived stress ( $\beta = -0.86$ ,  $p = 0.438$ ), social

support availability ( $\beta = -0.65$ ,  $p = 0.595$ ) and social support satisfaction ( $\beta = -0.157$ ,  $p = 0.199$ ) were not significant predictors. The overall model fit was  $R^2 = 0.044$ .

Women were asked whom they had or would confide in regarding a positive HPV result. Response categories included partner, doctor/nurse, family, friends, online support group or counsellor. Women could select more than one response. All participants ( $N = 107$ ) submitted at least one response – there were no missing data items for this question.

Whom have you or would you confide in regarding a positive HPV result (whether you have had one or not)?	N	Percent
Partner	69	62.2
Doctor/nurse	66	59.5
Family	50	45.0
Friends	50	45.0
Online support group	48	43.2
Counsellor	14	12.6

*Table 4.14: Frequency table of preferred confidant group for disclosure*

#### 4.6.6. Anxiety Over HPV Positivity

Participants were asked to indicate their anxiety surrounding a previous positive HPV result, or a putative positive HPV result in the future (e.g. following cytological surveillance, as part of follow-up after biopsy or after treatment). Response categories were originally on a five-item Likert scale ranging from 1 – Extremely anxious/worried, 2 – Very anxious/worried, 3 – Neither anxious/worried nor unconcerned, 4 – Not anxious/worried, 5 – Really not anxious/worried. Due to a small sample size, and none of the participants utilising the ‘Neither’ response, the original five item scale was reduced to a binary ‘Anxious/Not anxious’ response to reduce the number of items and to increase the number of responses per item. There were no missing data for this question.

Anxiety Over HPV Positivity	Number	Percentage
Please indicate your level of anxiety regarding a positive HPV result		
Anxious	79	73.8
Not anxious	28	26.2
Total	107	

*Table 4.15: Distribution of respondents by level of anxiety over HPV positivity*

Mean scores for social support availability (SSQN) and satisfaction (SSQS) and perceived stress score (PSS) for women grouped by anxious/not anxious are compared in Table 4.16.

HPV Anxiety		SSQN	SSQS	PSS
Anxious	Mean	1.47	3.66	21.32
	N	79	79	60
	Std. Deviation	1.11	1.06	2.59
Not anxious	Mean	2.41	4.55	19.78
	N	28	28	23
	Std. Deviation	1.34	.76	1.70
Total	Mean	1.72	3.89	20.89
	N	107	107	83
	Std. Deviation	1.24	1.065	2.47

*Table 4.16.: Mean scores for SSQN, SSQS and PSS for HPV anxiety*

Analysis of variance was used to test the second experimental hypothesis ( $H_{e2}$ ) which stated that there would be a significant difference in social support and perceived stress scores between women who indicated they were 'Not anxious' versus women who reported being 'Anxious'. ANOVA showed that between the groups of women ('Anxious'/'Not Anxious') mean scores for social support availability (SSQN) and social support satisfaction (SSQS) and perceived stress (PSS) were significant, as follows: social support availability (SSQN)  $F(1,84) = 13.81$ ,  $MSE = 13.48$ ,  $p < 0.001$ ; social support satisfaction (SSQS)  $F(1,84) = 16.16$ ,  $MSE = 11.04$ ,  $p < 0.001$ ; perceived stress (PSS)  $F(1,81) = 6.87$ ,  $MSE = 39.12$ ,  $p=0.01$

indicating that better social support and reduced stress are significant factors in reducing anxiety over HPV positivity.

#### 4.6.7. Reasons for Anxiety Over HPV Positivity

Women were asked to select reasons for anxiety over HPV positivity. There were six possible pre-defined items that women could select as responses, and an additional free text option to allow the entry of their own reasons if the items offered did not cover this. Response choices included: disclosure, stigma, fertility, health (worry over developing cancer), life/mortality (fear of dying), none of the above/not concerned. Respondents could select multiple responses, therefore the cumulative number and percentage of responses exceed the sample number (N = 107) and 100%. Of the 107 respondents who gave at least partial data to the questionnaire, all 107 gave at least one response to this question. Responses to the question are given in Table 4.17.

Reasons for anxiety	N	Percent
Cancer recurrence	67	61%
Developing Cancer	63	59%
Stigma	45	41%
Disclosure	41	38%
Dying	10	37%
Fertility	32	30%
Other (free text reasons)	10	8%
Not concerned	3	3%

*Table 4.17: Frequency table of responses to reasons for HPV anxiety*

The free text response box allowed space for up to 1,000 characters or several sentences. Ten individuals gave free text responses, which are given in Table 4.18.

Free text responses to reasons for anxiety	
Respondent	Responses/reasons for anxiety
8	I was worried and it was true. I have cervical [sic] cancer
9	Changing the way I interact with possible future partners or sexual encounters
13	Worried about passing this on to children
31	Severe embarrassment with outward signs (warts)
40	Peoples [sic] lack of knowledge and assumptions
47	The affects [sic] on my husband
61	The effects on my husband
63	Worried what if I have it in my mouth & what if I pass it onto my daughter by sharing a sip of squash every now & then. Well mainly scared of passing it onto her risking her life, she is only 2.5 yrs old. I'm also worried that my procedures was [sic] in 09.2013 back in Hungary as a [sic] have a doctor there I trust my result came back normal for the 3& 6 months smear but 2.2014 my result came back as Hpv? Parakariosis. I am scared to ask for a follow up smear in England as I know how spastic the system is but it'll be even a year till I can go to Hungary to have it checked. Anyway fingers crossed my immun [sic] system will fight it off. Hoping for the best & hope it'll be better for our daughter when she gets older. I do hope that hpv tests will be offered as a routine test at the gum clinics & the age limit for the smear test will be lowered to 16/18 or offered ASAP they become sexually active. I think it's very important.
66	My daughter died of Cervical Cancer arising from undetected and untreated HPV infection
71	Fear of infecting partner

*Table 4.18: Free text responses to reasons for anxiety over HPV positivity*

Free text responses to this question are further discussed in the discussion section.

#### *4.6.8. Embarrassment Over HPV Positivity*

Women who subscribed to HPV/cervical cancer related online support were asked to indicate their embarrassment over an HPV positive result. As with the previous question, the responses were originally on a five-item Likert style scale ranging from 1 – Very embarrassed, 2: Embarrassed, 3: Neither embarrassed nor unembarrassed, 4: Not embarrassed, 5: Really not embarrassed. Again, due to a small sample size, the original five item scale was collapsed

to reduce the number of items, but increase the number of responses per item. Responses to a three-item (Embarrassed/Neither/Unembarrassed) were given as follows:

Embarrassment Over HPV Positivity	N	Percentage
Embarrassed	49	46
Neither embarrassed nor unembarrassed	32	30
Not embarrassed	25	23.1
Missing data	1	0.9
Total	107	

*Table 4.19: Distribution of responses to embarrassment over HPV positivity*

Mean scores for social support availability (SSQN), social support satisfaction (SSQS) and perceived stress scores (PSS) were tabulated for each group of women (embarrassed, neither, not embarrassed) and are shown in table 4.20.

HPV Shame/Embarrassment		SSQN	SSQS	PSS
Embarrassed/ashamed	Mean	1.56	3.69	21.16
	N	49	49	38
	Std. Deviation	1.19	1.10	2.68
Neither	Mean	2.02	4.08	20.07
	N	32	32	26
	Std. Deviation	1.39	1.09	1.49
Not embarrassed/ashamed	Mean	1.65	3.98	21.11
	N	25	25	18
	Std. Deviation	1.11	.90	2.51
Total	Mean	1.72	3.87	20.80
	N	106	106	82
	Std. Deviation	1.24	1.06	2.35

*Table 4.20: Mean scores for SSQN, SSQS and PSS for embarrassment over HPV positivity*

Analysis of variance was used to examine for possible relationships between the three groups and perceived stress (PSS), social support availability (SSQN) and social support satisfaction (SSQS); but did not return any results significant to an alpha level of  $\alpha \leq 0.05$ . Embarrassment\*Perceived stress:  $F(2, 79) = F = 1.86$ ,  $MSE = 10.1$ ,  $p = 0.16$ ;

embarrassment\*social support availability:  $F(2, 103) = F = 1.40$ ,  $MSE = 2.14$ ,  $p = 0.25$ ;

embarrassment\*social support satisfaction:  $F(2, 103) = F = 1.50$ ,  $MSE = 1.68$ ,  $p = 0.22$ .

#### 4.6.9. HPV Knowledge Source

Women were asked to indicate from where they had or would obtain information about HPV. Response options included doctor, nurse, family/friends, internet, internet (researching the vaccine), NHS Direct, or 'Prefer not to say'. Women could select more than one response. Missing data analysis indicates that all respondents gave at least one response, there were no missing data for this question.

How did you find out about HPV	N	Percent
Doctor	50	45.0
Internet	50	45.0
Nurse	25	22.5
Family/friends	11	9.9
Internet/researching vaccine	6	5.4
NHS Direct	1	0.9
Prefer not to say	1	0.9

Table 4.21: Frequency table of responses for HPV knowledge sources

#### 4.6.10. Length of Use of HPV-Related Online Support

Women were asked to indicate how long they had been members of HPV-related online support groups. To put membership in context, it was cross-tabulated with stage of treatment to give an indication of whether membership was limited to the immediate period (the six to twelve months) of the treatment stage. Distribution of membership duration by treatment stage is shown in Table 4.22.



How long have you been using an HPV-related online support group	Have you ever been offered treatment for abnormal smear						Total
	No treatment yet	Biopsy	Treatment	Treatment and Follow-Up	Not had treatment	Not needed treatment	
I don't use them	0	1	1	2	0	0	4
A few weeks	0	4	2	0	0	0	6
A few months	0	3	5	2	0	0	10
About a year	0	2	2	6	0	0	10
Over a year	2	19	23	17	2	8	71
Prefer not to say	0	0	6	0	0	0	6
Total	2	29	39	27	2	8	107

*Table 4.22: Cross-tabulation of treatment stage and length of use of online support*

Women appear to retain membership of HPV-related online support groups beyond the immediate biopsy/treatment period, with 19 of the 29 women who required a biopsy (approximately a 6 month process) retaining membership over one year. Women who did not require treatment (N = 8) and women who had not received treatment (yet, N= 2) reported memberships of over one year. Data were recalculated – combining responses for membership of ‘a few weeks’ and ‘a few months’ and also combining responses for ‘about a year’ and ‘over a year’, to increase the number of responses per category. Comparison of mean scores for social support availability (SSQN), social support satisfaction (SSQS) and perceived stress scores (PSS) for these response categories are given in Table 4.23.

Duration of Online Support Use		SSQN	SSQS	PSS
I don't use them	Mean	1.87	4.17	18.75
	N	4	4	4
	Std. Deviation	1.00	1.13	1.50
A few weeks/months	Mean	1.68	3.96	21.53
	N	16	16	13
	Std. Deviation	1.05	0.95	3.30
A year or more	Mean	1.84	3.93	20.89
	N	81	81	66
	Std. Deviation	1.25	1.08	2.28
Total	Mean	1.81	3.95	20.89
	N	101	101	83
	Std. Deviation	1.20	1.05	2.46

*Table 4.23: Mean scores for SSQN, SSQS and PSS for length of online support use*

Analysis of variance did not indicate that length of online support membership was a significant factor for availability of or satisfaction with social support, or for perceived stress for this group. SSQN:  $F(2,98) = 0.11$ ;  $MSE = 0.165$ ,  $p = 0.89$ ; SSQS:  $F(2,98) = 0.89$ ;  $MSE = 11.89$ ,  $p = 0.91$ ; PSS:  $F(2,80) = 1.99$ ;  $MSE = 11.89$ ,  $p = 0.14$ .

#### *4.6.11. Reasons for and Outcomes of Online Support Use*

Uses for online support among women subscribing to HPV-related sites were examined using Likert scale agreement with statements about reasons for usage including: emotional support, exchanging information, helping others and sharing experiences. Two follow up questions examined the outcomes of online support use; women were agree to indicate their agreement with feeling better informed about HPV and with developing better acceptance of HPV. Small sample size meant that the original 5-item Likert scale (Strongly Agree, Agree, Neither, Disagree, Strongly Disagree) was reduced to 3 response categories to increase the number of responses per cell (Agree, Neither, Disagree).

Reasons women use online support								
Statement	Agree		Neither Agree nor Disagree		Disagree		Missing data	
	N	%	N	%	N	%	N	%
I use online support for								
Emotional support	74	73.2	20	19.8	7	6.9	6	5.6
Exchanging information	73	72.2	21	20.7	7	6.9	6	5.6
Helping others	65	60.7	6	5.6	7	8.9	29	27.1
Sharing Experiences	73	72.2	8	7.4	3	2.8	23	21.4
Since using online support I feel								
Better informed about HPV	68	63.5	8	7.4	5	4.6	26	24.2
Better acceptance of HPV	41	38.3	31	28.9	9	8.4	26	24.2

*Table 4.24: Frequency table of responses for reasons and outcomes of online support use*

Mean scores for social support availability (SSQN), social support satisfaction (SSQS) and perceived stress score (PSS) for each reason statement for using online support (exchanging information, emotional support, helping others and sharing experiences) are shown in Table 4.25.

		SSQN	SSQS	PSS
<b>I use online support to exchange information</b>				
Disagree	Mean	1.69	3.64	19.20
	N	7	7	5
	Std. Deviation	1.23	1.60	1.64
Neither agree nor disagree	Mean	1.38	3.84	20.3
	N	21	21	15
	Std. Deviation	1.04	.87	2.43
Agree	Mean	1.92	3.98	21.1
	N	74	74	63
	Std. Deviation	1.24	1.07	2.48
<b>I use online support for emotional support</b>				
Disagree	Mean	2.09	3.69	19.50
	N	7	7	6
	Std. Deviation	1.06	1.85	1.76
Neither agree nor disagree	Mean	1.50	3.84	20.4
	N	20	20	15
	Std. Deviation	1.30	.89	1.80
Agree	Mean	1.85	3.98	21.1
	N	75	75	62
	Std. Deviation	1.20	1.03	2.62
<b>Help Others</b>				
Disagree	Mean	1.85	3.76	20.0
	N	9	9	7
	Std. Deviation	1.16	1.41	2.08
Neither agree nor disagree	Mean	1.13	3.51	20.0
	N	12	12	8
	Std. Deviation	1.14	.96	2.00
Agree	Mean	1.89	4.01	21.1
	N	81	81	68
	Std. Deviation	1.21	1.04	2.54
<b>Share Experiences</b>				
Disagree	Mean	1.64	3.79	20.0
	N	8	8	6
	Std. Deviation	1.23	1.50	1.89
Neither agree nor disagree	Mean	.95	3.36	20.4
	N	11	11	7
	Std. Deviation	1.02	.93	2.23
Agree	Mean	1.92	4.02	21.0
	N	83	83	70
	Std. Deviation	1.19	1.03	2.54

*Table 4.25: Mean SSQS, SSQN and PSS scores for reasons for online support use*

Mean scores for perceived stress (PSS), social support availability (SSQN) and social support satisfaction (SSQS) for agreement with outcome statements for online support use are given in Table 4.27.

Better Informed About HPV		SSQN	SSQS	SS
Disagree	Mean	1.50	3.51	21.40
	N	16	16	10
	Std. Deviation	1.25	1.35	2.50
Neither agree nor disagree	Mean	1.99	4.05	20.18
	N	32	32	27
	Std. Deviation	1.42	1.01	2.33
Agree	Mean	1.77	3.98	21.19
	N	54	54	46
	Std. Deviation	1.05	1.00	2.49
Better Acceptance of HPV				
Disagree	Mean	1.65	3.74	19.80
	N	13	13	10
	Std. Deviation	1.34	1.31	2.35
Neither agree nor disagree	Mean	1.76	3.90	20.19
	N	39	39	31
	Std. Deviation	1.22	1.15	1.97
Agree	Mean	1.87	4.01	21.66
	N	50	50	42
	Std. Deviation	1.19	.95	2.61

*Table 4.26: Mean SSQN, SSQS and PSS scores for outcomes of online support use*

Multivariate general linear modelling was used to examine the third and fourth experimental hypotheses. H<sub>E3</sub> stated that women who reported agreement with the reasons for online support use – for emotional support, exchanging information, helping others and sharing experiences would show higher scores for availability of and satisfaction with social support, and lower scores for perceived stress. H<sub>E4</sub> stated that women who reported agreement with outcomes for online support use – being better informed about HPV and gaining better acceptance of HPV would show higher scores for availability of and satisfaction with social support and lower scores for perceived stress. Multivariate GLM did not demonstrate any significant outcomes.

## **4.7. Discussion**

### *4.7.1. Demographics*

Data from this section of the instrument was used to examine the first research question. The modal age brackets (25-34 years, 36% and 35-44 years 33.3%) mirror both the peak ages of incidence for cervical cancer (Cancer Research UK 2016) and the peak ages of internet use (ONS, 2017). A small percentage of women (5%) were in the 18-24 age bracket, indicating that they may have been subject to vaccination or had been diagnosed with HPV or CIN earlier than their first call for screening. The modal age brackets were also reflected in the ages of the participants who gave qualitative electronic interviews – all of whom were in the 25-34 or 35-44 age ranges.

The majority of respondents to the questionnaire reported being married (78%) with equal percentages of women reporting being divorced/separated and single (9.9%). Although women in settled relationships report less anxiety over HPV, the preponderance of women in settled relationships utilising online support may reflect their ages, or a preference among individuals to prefer peer support or 'weak tie' support (as offered by online support groups) as weak tie support does not presume the fulfilment of roles demanded by close support networks (such as family and friends) (Wright & Rains 2013; Wright & Bell 2003).

The overwhelming majority of respondents were of White British origin. According to the National Cancer Intelligence Network [NCIN] 2014, cervical cancer incidence among White females is 8.2-8.7 per 100,000 women. In Black females incidence is similar, ranging between 6.3-11.2 per 100,000 women. Incidence in Asian females is significantly lower, reported as ranging between 3.5 – 6.5 cases per 100,000 women. Therefore it would be reasonable to expect that the percentage of Black women using online support might be

similar to the rates seen among White females, but as is shown table 4.2 Black and British Minority Ethnic women are under-represented in the sample. A lower representation of Asian women is to be expected as, as far as is known, the reported incidence in Asian women is lower than seen in either White or Black population. Under-representation may also be due to a small sample size, as respondents to the survey comprised approximately six per cent of the total group (the membership of the online support group was in the region of 1,500 individuals).

#### *4.7.2 Cervical Screening History and Frequency*

On examining cervical screening history, the majority of women reported that they were being followed up for a previous abnormality (N = 62, 57.9%), and the next most frequent response was from women who reported being screened regularly (N = 21, 19.6%). Numbers of women who indicated frequent (additional) screening, and those that indicated they were only screened occasionally were almost identical ('Frequent/additional' N = 7 (6.5%); 'Occasional' N = 8 (7.4%)). Of the women who reported never having been screened, the majority of these were due to age ('Never/Not invited yet'; N=7). Cross-tabulation of cervical screening frequency and treatment history indicates that of these 7 women, 2 had had a biopsy, 3 had had treatment, 1 had refused treatment and 1 had not required treatment. This indicates that these women have been diagnosed with a cervical abnormality or HPV positivity prior to 24 years and 6 months old – the earliest that women can be invited for screening. These women may thus have been diagnosed on the basis of symptoms instead of screening, as per NHSCSP guidelines, which state that any woman reporting symptoms (abnormal bleeding patterns such as intermenstrual or post-coital bleeding)

irrespective of age or current recall status should be referred to Colposcopy for further investigation (NHSCSP, 2016). Qualitative data in the next chapter indicates at least one woman who was diagnosed with HPV and CIN at 22 years on the basis of symptoms.

Women were asked to indicate if they had been offered treatment, to explore at which stage of the diagnostic and treatment process online support users were at. Responses categories were “I have an appointment but have not attended yet” – indicating that women have been referred and offered an appointment but have not attended for colposcopy. An appointment has to be offered within two weeks of a test result (for high grade results) or within six weeks (for low grade results) (NHSCSP 2016). Thus women selecting this response are at the start of the referral/treatment journey. “I have had an appointment but not required treatment” – indicating that the woman had been referred for a colposcopy but neither a biopsy nor treatment was required. This occurs in cases where the colposcopic examination was normal or showed HPV only (please refer to figure 1.1, 1.2 and 1.3 in Chapter 1 for an explanation of the treatment algorithms); indicating that the woman was offered an appointment within the six week time frame and has been discharged back to primary care (her general practitioner). “I have attended a hospital or clinic and I have had a biopsy” – women who select this response will have been offered and appointment in the two- or six-week timeframe and colposcopic examination will have shown a low-grade lesion which indicates the need for a biopsy. This group and the previous group who did not require treatment correspond to the ‘liminal’ women who have had HPV infection confirmed by cytology/molecular diagnostics but for whom no neoplastic process has been identified, or for whom CIN1 has been diagnosed but a conservative management process has been recommended, or who show CIN2+ on biopsy and who are currently awaiting treatment. “I have attended a hospital or clinic and I have had treatment” – women



selecting this response will either have had a low-grade lesion that required biopsy, where the biopsy result that indicates the need for treatment in the case of CIN1, CIN2, CIN3 or possible invasive disease, or will have demonstrated a high grade lesion on colposcopic examination that required immediate treatment (bypassing the requirement for a biopsy). These women will be in the later stages of their treatment arc, corresponding to a timeframe of approximately 6 months since an abnormality was first identified by cytology. “I have had treatment and a follow-up test” – women who have selected this response have undergone treatment and have had a test-of-cure or are on long-term follow-up for minimally invasive disease (FIGO stage 1A1). The timeframe for these women is around 6-12 months, between 2-6 weeks for referral, 4-8 week between biopsy and treatment (depending on severity of abnormality at cytology and on colposcopy), and 6 months between treatment and a follow-up appointment (NHSCSP 2016, p.23). The majority of women reported being in the treatment arc, either having had a biopsy (N = 29, 27.2%), treatment (N=39, 36.5%) or treatment and follow-up (N = 27, 25.2%). Of women who had not had treatment, 2 had yet to attend their appointment (1.8%), 8 had not required treatment (7.5%) and 2 had refused treatment (1.8%). Reasons for treatment refusal were not given, and could not be followed up as the questionnaire was anonymous. The proportion of the population who have received treatment and/or treatment and follow-up would seem to indicate that women remain part of an online community once treatment is complete, either for further reassurance and support or to help others by sharing experiences/knowledge. Women who are awaiting treatment make up a small proportion of the group (N =2, 1.8%). Women for whom no treatment was required (N=8, 7.2%) would most likely make up the population of women who are HPV positive in the absence of CIN – the women who were the main focus of the research at the outset, the ‘liminal women’. This subset currently makes up only a small proportion of the research population at present (in

the absence of HPV primary screening). Similar to the women who remain once treatment is complete, these women may remain part of the group in the absence of a need for treatment in order to gain further reassurance from the experiences of others, to learn more information about their situation or because of doubts surrounding HPV negativity due to dormancy rather than clearance (Maglennon 2012; Gravitt et al. 2011).

#### 4.7.3. *Awareness of HPV*

Women were asked to indicate whether they were aware of the human papillomavirus (HPV). There were 26 instances of missing data, but of the remaining 81 individuals the majority indicated that they were aware of HPV (N = 79, 73.8%), with only 2 women reporting that they were not aware. As a follow-up question, to examine where women may initially have learned about HPV, respondents were asked whether or not they had daughters who were eligible for the HPV vaccine. If the majority indicated that this was the case, then awareness of HPV may have been gained through research into the vaccine. As indicated in the table, 77 women indicated that they did not have daughters eligible for vaccination (72%). All respondents answered the vaccination question. Awareness may thus be due to counselling at the point of screening (Everett et al. 2011) or self-directed learning after diagnosis (Rager 2006, 2004).

Women were asked to indicate whether or not they had had an HPV test. The majority of women (N = 75, 70%) indicated that they had had an HPV test. Of the negative responses, 1 chose not to participate (0.9%), 16 had not been tested (14.9%), 5 had not been invited yet (4.6%) and 10 women were not sure (9.3%). The HPV testing history question occurred after the question 'Are you aware of the human papillomavirus' (missing data N = 26), and was

answered by all 107 respondents, indicating that the awareness question may have been skipped because women did not understand the question (e.g. what was meant by awareness) or because they did not feel it applied to them, rather than through fatigue or attrition.

Of the HPV knowledge statements almost all of the respondents were aware that HPV may cause cervical cancer (106 of 107 respondents selecting this statement) although less women (among a group of women who subscribe to HPV-related online resources) selected as true statements regarding the relative prevalence of HPV ('HPV is the most common STI in the UK', 46 responses) and relative inefficacy of condoms in preventing genital HPV infection ('HPV may not be stopped by condoms, 54 responses). It should be noted that these questions asked women to select which items they believed to be true, rather than allowing a 'True'/'False' response. Therefore a missing response may not necessarily indicate a lack of agreement with the statement, and this factor is noted as a limitation to the study. However, this data may help to highlight that knowledge gaps remain in the awareness of the general public and that improving awareness of these issues may help reduce stigma associated with HPV.

#### *4.7.4. Disclosure Intention and Preferred Confidant Group*

Data from this section of the instrument were used to test the first experimental hypothesis – that social support scores may be a predictor of disclosure intention. The majority of women indicated that they would confide in someone regarding a positive HPV result (N = 94, 87.9%), with only 12 (11.2%) indicating that they would not disclose HPV positivity to anyone, and 1 individual preferring not to indicate their opinions on disclosure (0.9%). This

finding indicates that despite reservations reported in research about the disclosure of stigmatised conditions (Montgomery et al. 2008; Hult et al. 2012), the majority of women would still disclose their condition in current or future relationships. The question over preferred confidant group allowed multiple responses. 'Partner' was the most common response with 69 women (62.2%) selecting this category. Disclosing to or confiding in clinicians/nurses was the next most common response (N = 66, 59.5%). 'Family' and 'Friends' drew an equal number of responses (N = 50, 45%), with 'Online support' (N=48, 43.2% and 'Counsellor' (N =14, 12.6%) being less popular responses. Comparison of mean scores for social support availability and satisfaction was not possible as participants were able to select multiple responses. Respondents who had selected only family only vs. non-family were not large enough to infer statistical significance to any differences in social support. Thus from this exploratory data, it is reasonable to conclude that women do not use online support groups to confide their HPV-positivity to the exclusion of other forms of support (such as the physical support provided by family, friends and healthcare or mental health professionals). Disclosure to internet groups may only occur as an expedient to accessing the experiential aspects of online support.

#### *4.7.5. Anxiety Over HPV Positivity*

Data from this section of the instrument was used to test the second experimental hypothesis, that women indicating they were 'Not Anxious' about HPV positivity would report higher social support scores and lower perceived stress scores. Women were asked to indicate their level of anxiety on a 5-item Likert scale. However, lack of use of the 'Neither' category allowed for responses to be divided into 'Anxious' and 'Not anxious'. The group of

women who reported anxiety over HPV positivity showed lower mean scores for social support availability and satisfaction, and higher mean scores for perceived stress than the group who reported no anxiety over HPV positivity. This difference was statistically significant at a significance level of  $P < 0.01$ , and thus the second experimental hypothesis is accepted.

#### *4.7.6. Reasons for Anxiety Over HPV Positivity*

All respondents answered this question ( $N = 107$ ), although the total number of responses and percentage of response exceed the sample total as women were able to select more than one item in response. The modal response was “Health – I am worried about cancer returning” indicating that for 67 women (62.6%) HPV positivity made them anxious about cancer recurrence – it is not possible to know whether these women had invasive cervical cancer or CIN3 (this question was not asked as the researcher assumed that the majority of women asked might not know the difference between pre-cancer and cancer), or whether clinicians used the term ‘cancer’ as shorthand for ‘a highly abnormal pre-malignant lesion’. The meaning of HPV positivity for these women was anxiety over disease recurrence. Disease recurrence was also mentioned as an issue for women in the qualitative portion of the study, although framed somewhat differently – through uncertainty over HPV latency. The next most frequent responses surrounded fears about developing cancer ( $N = 63$ , 58.8%). Again, the question over whether women meant cancer or pre-cancer in their response still applies (but this is due to the wording of the question). Women reported similar frequencies for anxieties surrounding stigma (42.1%), disclosure (38.3%) and mortality (37.4%). Concerns surrounding fertility were the least commonly reported, with

29% of women reporting this as a concern – these may be due to the age ranges of the participants, the majority of women may have already completed their families. Only 3 women in the sample were not concerned, and 10 women reported “Other” concerns and gave free text answers. Of these, 5 of the 10 women reporting other reasons for anxiety mentioned fears of transmission either to their partners (through sexual contact) or to their children (through the sharing of household items such as drinking vessels, towels and bed linen). Issues around disclosure and stigma were second only (in frequency of response) to fears surrounding recurrent or developing cancer.

#### *4.7.7. Embarrassment Over HPV Positivity*

Encouragingly, less than half of the sample reported that they would be embarrassed by a positive HPV result (N=46, 46.2%), compared to 53.8% reporting ‘Neither’ (N=32, 30.2%) or ‘Not embarrassed’ (N= 25, 23.6%). As the majority of the sample had reported being in a committed relationship (78%), and that this factor was associated with decreased stigma/anxiety (Kwan et al. 2011; Filiberti et al. 1993) it follows that the majority of the sample did not feel any shame or embarrassment surrounding HPV positivity, in addition, the development of a collective identity as reported by Bane et al. (2005) may help to reduce shame. ANOVA was used to test the differences in scores for social support and perceived stress between the three groups (‘Embarrassed’/‘Neither’/‘Not Embarrassed’) was not significant at an alpha level of 0.05 and thus the null hypothesis is accepted.

#### *4.7.8. HPV Knowledge Sources*

Women were asked to indicate where they had or would obtain information about HPV. The modal response for the question of where women obtained their knowledge about HPV was split between 'Doctor' and 'Internet' (both N=50, 45%), indicating that for this group, looking up information on the internet was as likely as asking questions of a clinician. In addition, clinical information is only one form of knowledge, and the experiential knowledge of disease cannot necessarily be narrated by clinicians, hence the popularity of the internet as a source of information for the group. The uses for online support will be further examined in section 4.7.10.

#### *4.7.9. Length of Use of Online Support*

Women were asked to indicate how long they had been using an HPV-related online support group. The most common response was 'Over a year' (N = 71, 63.3%). Women reporting membership of 'About a year' and 'A few months' were equal (N = 10, 9.3%). Women who had been members for less time made up fewer of the responses (N = 6, 5.6%), with 4 women reporting that they did not use them (3.7%). These women may have been recruited from the Jo's Trust website, since the other two organisations (The Teal Ladies and BME Cancer Voice) are set up (on social media) as support groups, whereas the Jo's Trust site has information and research pages, a forum area where individuals can post questions or supportive message, but it is possible to access the information pages without interacting with other users. The remaining 6 women preferred not to indicate their length of membership (5.6%). When treatment stage was cross-tabulated with duration of membership it became apparent that the majority of women who reported membership of a

year or more (N = 81, 75.6%) were split fairly evenly between 'Had a biopsy' (N = 21, 19.6%), 'Had treatment' (N = 25, 23.3%) and 'Had treatment and a follow-up test' (N = 23, 21.4%). The remaining 12 had retained membership of an online support group despite not having or requiring treatment. The figures indicate that women retain membership of support groups for longer than the immediate biopsy/treatment period. Whilst it is possible that once the immediate need for information or reassurance is over women forget to leave support groups, the reasons for popularity of 'extended' membership (over a year) are explored in section 4.7.10. Women who reported not using online support groups also reported the highest mean scores for availability of (SSQN) and satisfaction with (SSQS) social support, and the lowest mean scores for perceived stress than all other groups (SSQN = 1.87, SSQS = 4.17, PSS = 18.75). Women who reported using online support for a year or more reported higher mean scores for social support availability (SSQN = 1.84, N = 81) and lower perceived stress (PSS = 20.89, N = 66), than women who had been using online support for weeks to months (SSQN = 1.68, N = 16; PSS = 21.53, N = 13), with satisfaction with social support being roughly equal in both groups (weeks/months SSQS = 3.96, N = 16; 'a year or more' SSQS = 3.93, N = 81).

#### *4.7.10. Reasons for and Outcomes of Online Support Use*

Data from this section of the instrument was used to test the third and fourth experimental hypotheses. H<sub>3</sub> stated that women who agreed with the reasons statements for online support use would show the highest scores for social support and lowest scores for perceived stress. However, women who agreed with all four statements showed the highest mean scores for perceived stress. Women who indicated agreement with 'I use online support groups to exchange information; showed higher mean scores for both



availability of and satisfaction with social support. Women who agreed with the statement 'I use online support groups for emotional support' had lower mean scores for availability of social support, but higher mean scores for satisfaction with that support. Women agreed with the statement that they use online support to help others showed the highest mean scores for both availability of and satisfaction with social support. Finally, of the reason statements for using online support, women who agreed with the statement 'I use online support for sharing experiences' also reported the highest mean scores for both availability of and satisfaction with social support.

Data from the outcome statements for using online support were used to test the fourth experimental hypothesis which stated that women who agreed with outcomes statements for online support use would demonstrated higher scores for social support and reduced scores for perceived stress. Women who agreed with the statement 'Since using online support I feel better informed about HPV' did show the higher mean scores for both availability of and satisfaction with social support than women who disagreed, but also higher mean scores for perceived stress than women who disagreed. Women who neither agreed nor disagreed with the statement showed the highest mean scores for social support and lowest mean scores for perceived stress than women who either agreed or disagreed with the statement. Women who reported agreement with the statement 'Since using online support I have improved acceptance of HPV' showed the highest mean scores for availability of and satisfaction with social support, but also the highest mean scores for perceived stress. Multivariate GLM analysis for agreement with online support use reasons (emotional support, exchanging information, helping others and sharing experiences) against social support availability (SSQN), social support satisfaction (SSQS) and perceived stress (PSS) did

not indicate that differences between groups were significant (please refer to Appendix 3 for statistical tables for outcomes for this analysis).

#### **4.8. Conclusions**

The aims of the questionnaire study were to examine the characteristics of a population of HPV-related online support users; and to explore the reasons for and outcomes of online support use among women in terms of increased availability of and satisfaction with social support, and reduced perceived stress. The research questions asked if the demographic characteristics of HPV-related online support users reflect those of the general screening population, whether there was a relationship between increased social support and disclosure, and whether the use of online support (in terms of emotional support, exchanging information, helping others or sharing experiences) or the outcomes of using online support (feeling better informed about HPV, or gaining better acceptance of HPV) were associated with increased scores for social support and reduced scores for perceived stress. The four experimental hypotheses reflected the aims and the research questions.

The first hypothesis postulated that there would be a significant relationship between increased social support scores and the propensity to disclose a possible positive HPV result. The linear regression of disclosure intention and social support indicated that social support availability (SSQN) and social support satisfaction (SSQS) were not significant predictors of disclosure. Therefore in order to avoid Type II errors, the null hypothesis must be accepted – for this population, there is no significant relationship between social support and disclosure.

The second hypothesis suggested that there would show a significant relationship between a reported lack of anxiety over HPV positivity and increased scores for availability of and satisfaction with social support. Women were asked to indicate their anxiety over HPV, and these responses could be divided into 'Anxious' and 'Not anxious'. Comparison of mean scores for the dependent variables was made and indicated that the group of women who reported a lack of anxiety over HPV showed increased scores for social support and availability and reduced scores for perceived stress. Therefore to avoid a Type I error, the null hypothesis (that no significant relationship would exist between social support and/or perceived stress and anxiety over HPV positivity) must be rejected.

The third hypothesis made the assumption that agreement with the uses of online support (for emotional support, to exchange information, to help others or to share experiences) would be associated with increased social support scores and reduced perceived stress scores. The fourth hypothesis made similar assumptions, but focused on the outcomes of online support (being better informed about HPV and/or gaining better acceptance of HPV) – predicting increased social support scores and reduced perceived stress scores for the women who agreed with these outcomes. A multivariate generalised linear model of the independent and dependent variables did not indicate any significant outcomes at an alpha level of 0.05, so in order to avoid a Type II error, the null hypothesis must be accepted – no significant relationship exists between online support uses or outcomes and social support scores and perceived stress scores.

#### **4.9. Summary of Findings from Quantitative Data**

- The majority of women subscribing to an HPV-related online support group were between 25-44 years (N = 75, 69.3%), and had had an abnormal smear result (N = 96, 89.75%), an HPV test (N = 53, 49.5%) and had had either a biopsy, treatment or were on follow-up post-treatment (N = 95, 85.5%).
- The majority of women were aware of HPV (N = 79, 73.2%), although there were missing data for this question.
- The majority of women would confide in someone about HPV positivity (N = 94, 87.9%), with 'Partner' being the most popular choice of confidant (N = 69, 62.2%).
- Of the HPV knowledge statements, the relative ubiquity of HPV and the inefficacy of condoms in preventing transmission were the least frequently selected knowledge statements (N = 46, 42.9% and N = 53, 49.5% respectively).
- Women who reported anxiety over HPV positivity reported lower mean scores for social support availability and satisfaction and higher mean scores for perceived stress than women who reported they were not anxious about HPV positivity.
- When selecting reasons for HPV anxiety, fears over developing or recurring cancer were the most commonly cited reasons, with fears about stigma and disclosure being the next most common reasons. Free text entries for anxiety focused on fears over transmission to partners and children and of stigma.
- There were no significant relationships between uses of online support (emotional support, exchanging information, helping others or sharing experiences) and either increased scores for social support or reduced scores for perceived stress.

- There were no significant relationships between outcomes of online support use (feeling better informed about HPV, or gaining better acceptance of HPV) and either increased scores for social support or reduced scores for perceived stress.

## **Chapter Five – Qualitative Data Analysis**

### **Study 2: Electronic Interview Study Examining Lived Experience of Users of HPV-Related Online Support**

#### **5.1. Introduction**

The previous chapter gave details of the aims, methods, analysis and findings for the quantitative study data derived from questionnaire responses, Study 1. This chapter will examine the qualitative study – Study 2 – conducted to explore women’s lived experiences of HPV positivity and the role that online support played in those lived experiences. The study employed the follow-up explanations model, using qualitative data to add depth and explanations to the findings of the quantitative data analysis.

##### *5.1.1. Aims of the Electronic Interview Study*

The research questions introduced in Chapter 1 examine the possible representation of HPV or HPV & CIN as a biographical disruption, contributing factors and the role(s) online support might play in the management of the self, stigma and biography during the diagnostic and treatment process. The qualitative study aims to answer these questions by examining women’s experiences of HPV positivity and their interactions with and experiences of the online support processes they solicited during the diagnostic and treatment process. The aims for the qualitative electronic interview study are as follows:

1. To recruit a population of women from online support resources to participate in and obtain qualitative data from electronic interviews.
2. To analyse transcripts of qualitative data obtained from electronic interviews to examine women's experiences of HPV positivity and online support and identify themes that might be common to their individual experiences.
3. To document the ways in which women interact with online resources and support and to examine how both HPV positivity and online support have impacted on their lives.

#### *5.1.2. Research Questions*

Research questions were formulated to fulfil the aims of the qualitative interview study. These were informed by the literature reviewed in the first three chapters which examined the psychological and sociological impacts of HPV positivity, and the effects of illness on identity, and the exploration of phenomenology in the third chapter. The research questions for the qualitative study are as follows:

1. Does a diagnosis of HPV or HPV & CIN represent a biographical disruption?
2. What factors might contribute to this?
3. What role(s) might online support play in the management of the self, stigma and biography during the diagnostic and treatment arc?

## **5.2 Interview Schedule/Questions, Identifying Sample Populations**

An interview schedule of questions was drawn up, drawing on the topics identified in the literature review. Broad themes for questions included meaning-making, asking participants to reflect on their feelings surrounding the diagnostic process. Additional questions included issues of biography, asking women whether a diagnosis of HPV had affected their views of themselves or their outlook on life. As the interviews aimed to capture lived experience, the interview schedule also asked for description of typical days and 'good' days. Questions prompting reflections on both physical social support and online support were also included. The interview schedule can be found in Appendix 6. The structure of the schedule drew on the writing of Smith, Flowers and Larkin (2009, p.60) asking comparative, descriptive, evaluative, narrative and circular questions to encourage participants to engage in reflection and self-reflection around the topics raised. This was particularly important as all participants opted for electronic interviews, meaning interviewer prompting was minimal. The interview schedule was forwarded to the supervisory team for review and comment.

### **5.2.1 Identifying and Approaching Sample Populations**

Entering these terms into internet search engines returned results for Jo's Cervical Cancer Trust, the Eve Appeal and for several blogs written by women narrating their experiences of suffering from cervical cancer. The Eve Appeal is a charity dedicated to research into and support for women suffering from cancers of the female genital tract. The Eve Appeal did not respond to or acknowledge several approach emails and was thus excluded from the study. Blog authors based in the UK were also approached via email (through 'Contact' buttons/forms) with the approach letter found in Appendix 5, but no responses were



received. The researcher decided not to post in the comments on blogs to attempt recruitment of individuals commenting on blogs, as she perceived these to be private online spaces as opposed to public ones (Hunsinger & Senft 2013, p.145). Positive responses were received from Jo's Trust, which, according to the 'About Us' section of the website is 'the only UK charity dedicated to women affected by cervical cancer and cervical abnormalities' (Jo's Trust 2017). The charity provides an online space for forums within the website for women who suffer from cervical abnormalities, including separate forum areas for each grade of abnormality (as per the NHSCSP reporting guidelines), including a dedicated space for 'HPV only' women; and a forum board for each stage of cervical cancer. The website hosts research pages whereby researchers can post adverts for their studies, which users can visit and sign up to of their own volition. In order to post a research advert on the hosted pages, a copy of the project proposal, participant information sheet, consent form and interview schedule plus a link to an electronic copy of all of these items (hosted at SurveyMonkey, to allow participants to register their consent electronically) was submitted to the Research Department at Jo's Trust Head Office for review in order to gain permission to post on their research pages. In total, two individuals were recruited via Jo's Trust research pages.

### *5.2.2. Social Media Populations*

In addition to posting with Jo's Trust a number of groups were identified on Facebook – the names of these have been redacted in order to preserve the confidentiality of the participants. Forum sources on Reddit were excluded as there was not enough continuity between threads/posters, and setting up a private group would take time in comparison to approaching established groups. Four social media groups were identified, with memberships

ranging from 800 to 2,000 members. Administrators for each group were identified and approached using Facebook messaging using the text in the approach letter given in Appendix A, and permission to join each group was granted. However, despite being permitted to join each group, only one group's administrator specifically responded to the approach message expressing a willingness to support the project and to post the research advert on the researcher's behalf, with the following stipulations:

*'The only thing I would ask is that you don't contact people about your research directly (either via comments on posts, private messages or postings) – unless they come to you of course.'*

(Gatekeeper, personal communication, Feb 2017)

### 5.2.3 Gatekeepers – The Recruitment Process

All of the groups encountered (detailed in Chapters Four and Five) were closed sites, which required registration and a request to join the group before users were allowed to post to forums or join discussions. Within each of these groups, gatekeepers were approached to request to access to participant populations. This permission was granted, but only one administrator responded positively to the approach message. All posts about the research (using the text from the approach letter and links to the SurveyMonkey consent process) were forwarded to the group by the administrator following discussion and agreement with the researcher. In addition, as shown above, the administrator requested that no direct requests were made by the researcher to group members either by posting, commenting or by direct messaging. Thus the administrator fulfilled the role of gatekeeper to the research population

in this context. According to (Broadhead & Rist 1976) gatekeepers are persons who are able to arbitrate access to a social role, field setting or structure.

Stewart & Williams drew attention to gate-keeping issues in online-mediated research including the danger of such groups being 'over-researched', stating that: 'of the 60.5 million current users, many may become nonchalant toward the myriad of questionnaires, interviews and focus groups they are asked to partake in on a weekly basis'. Williams gave an example of an online group who were sampled by an undergraduate class in the US who had, the evening before, been sampled by a Master's student in the UK some 12 hours earlier. They concluded that successful gate-keeping encounters relied on trust, rapport and the instance of shared history (Stewart & Williams 2005).

The gate-keeping role fulfilled by staff at Jo's Cervical Cancer Trust was very formal, and the documentation review undertaken was in very similar in rigour and formality to the University ethical approval process. From the perspective of Stewart & Williams conclusions above, trust was established through the submission of personal details such as curriculum vitae and evidence of professional qualifications, along with the documentation review procedures. In addition, contact details for the researcher's employer and the University Graduate School Office were supplied in case of any questions about the researcher's place at the University or place of employment.

The gate-keeping role for peer support groups run through social media platforms was fulfilled by volunteers – administrators or founders of groups – but the approach to research was met with the same professionalism as was received from the University and from Jo's Trust. 'Admins' were sent the same covering letter as the charity (by Facebook messenger or by email to addresses specified in 'Contact Us' sections of websites). In the case of Facebook

groups, an email address for an admin was requested so that all researcher information, project proposal documents and SurveyMonkey/CallForParticipants.com links could be forwarded. As previously stated, only one administrator responded to the approach message, from the five groups that were contacted – several attempts at approach (three in all – original and two follow-up messages) were made to the administrators who did not respond, but after the second follow-up message the researcher stopped contacting the groups.

The successful gate-keeping encounter within a social media support group bore out Kerekes' (2006) recommendations of shared interest or common ground as, serendipitously, it happened that the administrator for the Facebook-based support group was an alumnus of the University, and aware of the need for rigour in the research proposal and ethical approval process; thus it was easy to find common ground which greatly facilitated the approach process.

### **5.3. Data Analysis**

Data from online interviews was analysed using thematic analysis (TA). Thematic analysis is one of the most common and perhaps oldest form of qualitative data analysis (Sandelowski 1995). According to Braun & Clarke (2006) it is particularly useful for the relative novice to qualitative data analysis, describing it as “a foundational method for qualitative analysis” and the “first that researchers should learn”. Thematic analysis involves the examination of qualitative (text-based) data in order to identify themes within the text that are apposite to the phenomenon under scrutiny (Guest et al. 2012, p.3). Braun and Clarke (2006) describe six stages to thematic analysis – familiarisation with the data (transcription), generating initial codes, searching for themes, reviewing themes, defining and naming themes

and producing the report. Sandelowski (1995) also advises getting a 'sense of the whole' (or 'orienting gestalt'). This has been done with the qualitative data here by reflecting on the tone and content of each narrative as a whole, prior to identifying individual themes within each narrative. The point of identifying themes is a pertinent one in two respects. Anzul et al. (2003, p.208) warn that themes do not 'reside' in the data, waiting to be discovered – that thematic analysis is not a passive act – but that the process of identifying and coding a theme is an active process on the part of the researcher. Foster and Parker (1995, p.204) echo this idea of an active researcher, stating that analysis of the material is 'a deliberate and self-consciously artful creation' by the researcher to argue their case to the reader. The other issue in the case of identifying themes is deciding what 'counts' as a theme. This is particularly significant in the case of this research as the number of transcripts is limited. Braun and Clarke do not specify that a theme has to be a specific size (i.e. running to several sentences). In the case of this research, as will be discussed later, a theme was identified as an item that was mentioned by more than one participant.

Thematic analysis was chosen as it is an accessible and flexible means of analysing qualitative data that fits within the epistemological and theoretical assumptions of the research (as described in Chapter 3) with a clear process for undertaking the analysis and a good history of use in the field of HPV research (Standifer 2016; Batista Ferrer et al. 2015; Seale et al. 2012).

#### **5.4. *Data from Electronic Interviews***

The following sections will examine the themes that were identified in the stories of the women who agreed to participate in online research interviews, as related to and interpreted

by the researcher. Three women were recruited to the online interview arm of the study. As mentioned in the research methods chapter, several online support groups were approached, with memberships ranging from 800 to 3,500 people. Originally, seven women displayed an interest in and signed up to the study, going through the consent process, receiving participant information and a set of questions, but of these only three returned responses to the questions. Respondents who did not return answers were sent two follow up emails, ten days apart. If they had not responded after this time, they were not contacted again. Two participants returned several pages of answers and surrounding narrative that contained lots of description and motifs. One participant returned much thinner data – approximately one A4 page, but this still contained some profound statements on the effect HPV positivity and CIN had had on her life.

### **5.5. Participant Stories and Narratives**

A brief summary of women's stories follows, outlining their situations, followed by reflections on the structure of their narratives. A fuller exposition of the themes and sub-themes that were identified in the retelling of their experiences will follow.

#### **5.5.1. Jay's Story**

Jay was recruited via a social media support group, of which she is a founder and group administrator. Jay was 34 years old at the time of her interview. Jay is married. Her husband is aware of her HPV status, and is supportive of her, to the point of becoming a member of the support group. They have no children. Jay has multiple co-morbidities including asthma,

fibromyalgia and lupus, and works from home. She has been an active member of an online support group for approximately five years. Jay was diagnosed with CIN1 and HPV in 2011 and decided to “research her way to peace” after finding very little information available through her healthcare practitioner. Overall, Jay felt the diagnostic and treatment pathway was a long, drawn-out process that was at times confusing, with conflicting information being given.

### 5.5.2. *Claire’s Story*

Claire was recruited after seeing the research advert that had been placed with the Jo’s Trust website, as she was a regular user of the site and forums. Claire was the youngest woman to participate, at 22 years old. Claire is in a relationship, but she and her partner have no children. Claire’s partner was originally unaware of her HPV status/the role of HPV in CIN at first, although they ‘talk more openly about it now’. Claire’s responses/narrative indicate that she had to push hard to be referred to Colposcopy, attending her GP surgery ‘on a few occasions’ as she was below the age for screening and thus would not have been eligible for her first screening test for another three years, at age 25. Similar to Jay, Claire reported that healthcare practitioners gave conflicting information, which prompted her to research her symptoms online. Claire felt that both her diagnostic process and resulting condition were ‘somewhat different to the norm’ as she had developed symptoms at an early age (22 years) and because she had received all three doses of the HPV vaccine at 13/14 years of age. Claire feels her experiences will help her be a better healthcare professional. As will be made clear in a deeper analysis of her narrative, Claire experiences an onset of symptoms (similar to the ‘creeping onset of symptoms described’ by Bury) and her repeated efforts to obtain a referral

for colposcopic examination constitute a response to disruption through the 'mobilisation of resources' (Bury, 1991; 1982).

### 5.5.3. *Jo's Story*

Jo was recruited via the Jo's Trust website, having used their 'Ask a Professional' service (it should be noted here that the researcher is not a member of the 'Ask a Professional' panel). Jo is a 25 year old student with one daughter. Jo was diagnosed with pre-cancerous cells following a miscarriage in February 2016. Jo feels that due to her career choice, she is generally well-informed on health matters although she was 'shocked' to learn about the role of HPV in her diagnosis. She reports that she was aware 'that it is extremely common.' Jo felt that overall the experience was positive, as she hopes to become a nurse specialising in Gynaecology and that her own experiences will improve her practice.

### 5.6. ***Reflection on Narratives***

Each narrative represents a very different facet of the lived experience of CIN treatment, the lived experience of HPV positivity and the uses each respondent made of online support (one social media, one via an online professional, one via an internet forum). An overall analysis of each of these narratives is given below. A more detailed examination of the super-ordinate and sub-themes will follow.



### 5.6.1. Reflection on Jay's Narrative

Jay's narrative uses very emotive and descriptive terms when narrating her lived experience of the diagnostic and treatment process. There are several references to darkness, oppression and uncertainty:

*'the possible cancer diagnosis hung over me like a dark cloud',*

*'when I finally did hear back that the biopsy was fine, I was very relieved; only to be quickly overshadowed by the news that I'd need the LLETZ procedure.'*

*'another fling into the unknown'*

In the context of her narrative, Jay literally describes being thrown into a new world of the unknown, uncertainty, illness and anxiety; which would shortly become another new world of clinical terminology and treatment that had already existed without her knowledge of it. Jay also mentions the physical experiences, including pain and panic during the diagnosis and treatment process in great detail:

*'I had to go on bed rest... I felt like I had a blow torch burning inside – constantly.'*

Thus the meaning that Jay seems to put on the experience is first one of pain and anxiety; followed by fear and waiting. Jay mentions that her partner was fully apprised of her disease status, and supportive of her to the point of becoming a member/fellow admin of her support group and accompanying her to appointments. The second half of her narrative describes the formation of the support group; the role she played in setting up the group and leading discussion with others. The meaning of her lived experiences after diagnosis is focused on research and learning for herself – both about the virus and about coping strategies; and then on teaching, supporting and informing others. Toward the end of her narrative, Jay

speaks of the more positive aspects of HPV positivity, describing it as ‘a positive experience overall’ whilst being aware that HPV may recur in the future.

#### 5.6.2. Reflection on Claire’s Narrative

Claire’s narrative is more detached, factual and clinical than Jay’s. This may be in part due to her nurse training. She does not describe her symptoms or refer to pain. The overriding meaning apparent in the first half of her narrative is that of difference, struggle, and frustration – the struggle to be heard and to be diagnosed at all. Claire felt her case was different ‘to the norm’ due to her age at diagnosis – she was below the age for the commencement of screening (‘first call’) – and despite reporting her concerns and symptoms was told to monitor them and return to her GP if they returned:

*‘I presented at the GP on a few occasions with some abnormal symptoms; I was advised to monitor them and return if they returned.’*

*‘I spoke to my GP over the phone and asked about the possibility of having a smear test... my GP informed me that ...I was not eligible to have a smear because of my age.’*

She reports attending the GP surgery on ‘a few occasions’ and being turned away. These instances, combined with the extended wait on the waiting list once referred amount, almost, to a barrier to accessing healthcare. Claire also reported frustration at the length and pace of the process. Thus the meaning for Claire in the first part of her interview narrative is of waiting and frustration. She reports that once she was finally diagnosed, she found the formal ‘Ask a Professional’ service offered by a cervical cancer charity forum to be:

*‘...the most valuable information I received throughout my whole experience. My questions were answered thoroughly...’*

The second half of Claire's narrative focuses on her interpretation of the effect of her experience on self/biography. Due to the (deliberate) minimal presence of the interviewer, respondents were able to choose the questions they answered. Claire was the only individual to give specific details at length about the effect of the experience on the self. In terms of the benefit-finding aspect of meaning-making, Claire used the experiences she passed through during the diagnostic and treatment processes, and the knowledge of HPV she gained to improve her practice as a healthcare professional. Claire also reports that she has gained personal resilience from the process. Interestingly, Claire was the only individual to report a delay in disclosing her HPV positivity to her partner:

*'I never mentioned the likely cause being HPV until I had digested the information myself. I have since discussed it with him and talk more openly about it with him now. I didn't want to cause any unnecessary worry or anyone else.'*

### 5.6.3. Reflection on Jo's Narrative

Similar to Claire, Jo is also a nursing student, and this, as with Claire, may have shaped the format of her narrative, which was detached, brief and factual – although she does on occasion describe emotions and mindsets as single words (e.g. 'confused' ...'positive'). Jo's narrative was the shortest – with some of the detail being provided in text form as a response to the invitation/introduction email and some of the detail being provided as short sentences and at times single words annotating a print out of the original interview schedule, appended as a photograph. This was printed out and typed up in the same manner as the other interviews. Due to the nature and brevity of her responses, Jo's data is the 'thinnest' of the three narratives, but undoubtedly contains perhaps the most profound episode of biography reported in the study:

*'To cut a long story short I suffered a miscarriage in Feb 2016 and the smears ever since have come back as pre-cancerous and I believe it was the management of the miscarriage that contributed to this.'*

This quote was perhaps the most difficult portion of any of the narratives to interpret, because the researcher-practitioner mindset was aware that this was an unlikely event – the knowledge of HPV incidence, prevalence and a timeline from infection to the appearance of microscopic abnormalities makes the mismanagement of her miscarriage as a likely cause improbable. Unfortunately, Jo did not respond to emails asking follow-up questions to elucidate what she meant by her statement. Jo doesn't report on the emotional aspects or meaning of her miscarriage – emotions such as grief, anxiety, guilt or other negative emotions are not mentioned. Nikčević & Nikolaidis (2014) examined meaning making in 127 women post miscarriage and report that by seven weeks post-loss, over half of the women reported that they had found meaning/understood why the miscarriage occurred, and that providing information about the cause of the loss was associated with finding meaning. As a researcher (informed by practitioner knowledge) the meaning of Jo's truth – that her miscarriage caused her cervical abnormalities – is that she needed (at both the time of the loss of her pregnancy, and at the time of her HPV/CIN diagnosis) better counselling and better HPV information provision than she received.

### **5.7. Themes**

During analysis of the qualitative data, three major themes became apparent. The first two of these themes contain three subthemes. The content of the themes and subthemes is discussed below.

## Theme 1: Information, Stress and Anxiety

### 5.7.1. Too Much Information: Cancer, Cancer, Cancer

Jay reports in her narrative that she received an information leaflet about cervical cancer along with her result letter informing her that abnormalities had been found on her cervix during a routine screening appointment:

*'I received a letter stating that I would need to see a Consultant because abnormalities on my cervix had been found... Along with this letter was a cervical cancer leaflet. At first I felt mortified, had I just been told that I had cancer? I read and re-read the letter a few more times & read the leaflet, & then realised that cervical cancer was a possible outcome. Would it perhaps have been more appropriate to hand out such a leaflet, if needed, later in the process? On the other hand, handing out such a leaflet at this early stage may help some ladies to realise the gravity of their situation... So I feel quite conflicted about the usefulness of the literature – at such an early point anyway. In my case, I felt, it added to my stress & anxiety levels.'*

The inclusion of the cancer leaflet with her result letter caused Jay much anxiety and confusion, and she reports feeling conflicted about its usefulness. Jay had to read and re-read both the letter and the leaflet 'a few more times' to ensure that she had the information correctly. She states early on in her responses that her diagnosis was made following a routine screening appointment, in other words one with no expectation of an abnormality being identified. Her use of the words 'hand out such a leaflet, if needed' suggest that she would have learned more or been less anxious if she had had the chance to ask questions face-to-face when learning that cervical cancer was a possible outcome to her diagnostic and treatment process. She also states 'if needed', indicating that as she was not diagnosed with cervical cancer this information was not required, or at least not required this early on in the diagnostic journey. Jay's thoughts echo those found in a study of breast cancer patients by Arden-Jones *et al* who found that attempting to give information to patients regarding options

for genetic testing at the time of a breast cancer diagnosis was ‘too much too soon’ (Ardern-Jones et al. 2005).

Jo similarly reports that her experience of the Jo’s Trust website was a case of too much information, stating:

*‘The Jo’s Cancer Trust website [sic] is informative, but having the word ‘cancer’ all over the pages is very daunting and scary’.*

Both women were thus made anxious by the implication through written communications – either by letter or by the signposting on a website – that their diagnosis meant cancer, even though (in both cases) they did not have cancer. Jay felt that this information might have been better given later on in the treatment process if and when required rather than at the outset, giving her more time to be accustomed to the possibility of cancer as a possible health outcome. The concept of too much information led to increased anxiety due to the fear of cancer for both women.

#### 5.7.2. *Conflicting information*

In addition to the concept of information furnished too soon (in the participants’ opinion), the participants also reported that they were given conflicting information. Jay notes that:

*‘When I finally did hear back that the biopsy looked fine, I was very relieved; only to be quickly overshadowed by the news that I’d need the LLETZ procedure. Again, another fling into the unknown.’*

The mention of the biopsy being 'fine' only to be followed by the news that Jay would require further and more invasive treatment meant more confusion and more anxiety, following an initial outcome that seemed to indicate that Jay was healthy.

Jo also reported confusion over conflicting information, albeit from another source – whereas Jay's experience was conflicting information from her doctor, Jo experience confusion over reports of other's experiences. Feeling that she required further information and answers to questions following her diagnosis Jo turned to the Internet. She reports that she did not get involved with online support but that she visited forums on online sites devoted to cervical cancer and HPV. She reports that she felt:

*'...confused as people have such different procedures and experiences.'*

Whereas Jay's confusion may have arisen from a point of practice (and will be discussed in another section surrounding themes derived from a practitioner's perspective), Jo's was due to examining others' experiences online. Studies examining peer support in mental health have shown that the use of shared experience (Moorhead et al. 2013, Repper & Carter 2011) is often helpful in the management of anxiety for individuals who have been newly diagnosed, however this was not the case for Jo. In both cases, information was a source of anxiety for both women when it conflicted with previous data.

### *5.7.3. Quality of Information, Time to Assimilate*

The third subtheme associated with information was the quality of the information obtained. Claire reports that, feeling that some of her questions had not been answered, she visited an online source:

*'It was at this point that I sought advice from the online ask a medical professional service offered by 'Jo's Cervical cancer trust [sic]'...This was the most valuable information I received throughout my whole experience. My questions were answered thoroughly and it was here that I realised the likelihood of my cell change was a result of having HPV.'*

The provision of good quality information by a professional (a trusted position) which answered Claire's questions at a time, place and pace of her own choosing, and delivered in a manner that she was able to digest, print, save and/or re-read if necessary was key to her notion of the value of the information.

Similarly, Jo reports that information from friends (particularly nursing friends) was more valuable as it was good quality information. Jo also mentioned that the quality of information online can be variable:

*'There are a lot of forums out there which are not always effective and can be misconstrued.'*

When asked if she felt she received different information/support from different groups, she replied in the affirmative:

*'Yes, support from my nursing friends is more evidence based.'*

The mention by both individuals of 'valuable' information [Claire] and effective, evidence-based information [Jo] reiterate findings by Cole et al. (2016), who asked medical professionals and nonmedical individuals (informed individuals such as the chairs of dedicated charities, such as HIV and diabetes) to score the health advice for HIV, chickenpox and diabetes on amateur internet discussion boards (on Mumsnet, Reddit and Patient) on a scale of 5 to 25 (with 5 being the highest quality and 25 the lowest quality). Cole et al. found that good quality information appeared four times as often as poor quality information, and that the quality of information varied by condition (with poor advice/information being given out



for chickenpox occurring far more often than that for HIV [2 instances] or diabetes [1 instance]. Healthcare information surrounding HPV may be more variable due to the stigmatised nature of the disease (Kosenko et al. 2014) but both individuals were able to recognise the value of good information and to dismiss information that was poor.

### *Theme 2: Uncertainty*

The next theme that became apparent in the individual narratives was that of uncertainty. Within this theme, the subtheme of waiting was most apparent within the narratives, specifically the length of time spent waiting for results and appointments, which added to uncertainty and thus anxiety.

#### *5.7.4. Waiting*

Jay mentions the time spent waiting for results or appointments at several points throughout her narrative:

*'...given the wait times involved, the possible cancer diagnosis hung over me like a dark cloud.'*

*'...my first appointment with the Consultant was about a month later – seemed like a lifetime.'*

*'Again, there was a wait of about 3-4 weeks before I heard anything more – a very scary wait.'*

*'I would say that, I felt, the timescale here in the UK (from positive pap smear to the all clear) was a very long & drawn out process. I'd like to think that since 2011, the NHS has found ways to reduce the wait times involved. If it hasn't, then such wait times (between appointment & results etc.) should be looked at with a view to reducing them. That six months (approximately) was a very difficult time; and*

*without the support of my HPV group & my husband & family, together with my research, I wouldn't have coped half as well as I did.'*

The time spent waiting for appointments or results contributed greatly to Jay's anxiety, and again she mentions the possibility of a cancer diagnosis. The extended waiting time represents a period of uncertainty in her life, where, as Forss et al. (2004, 2001) state, 'neither health nor disease is confirmed nor excluded'. Kosenko et al. (2012) highlighted areas of uncertainty in their study of 25 women newly diagnosed with HPV: diagnosis meaning, potential for disease progression, finances, source of infection, disclosure, sex and reproduction and the HPV vaccine. Although not specifically mentioning HPV until later in her account, the focus of uncertainty in Jay's story centres on the potential for disease progression. Jay reveals that she disclosed her disease to her husband (who was supportive) and in a follow-up question she revealed that they did not plan to have children, thus ruling out anxiety over disclosure and fertility/reproduction. Jay also notes that the support received from the online support group and from her partner and family was very valuable during the waiting process.

Claire's story indicated similar anxieties – fear at the possibility of disease progression:

*'I presented at the GP on a few occasions, with some abnormal symptoms; I was advised to monitor them and return if they continued. They did continue and I was then referred to Colposcopy as a routine measure. At the point the nurse mentioned that this could be down to 'abnormal cells'. I took it upon myself to do some online research regarding my symptoms and I was aware my symptoms resembled those of cervical cancer.'*

*'A few weeks later I attended a walk-in GUM clinic as my concerns and symptoms were ongoing. I was hoping to rule out any infection that may be causing my issues. Here, the doctor informed me that from an internal examination he could see an abnormal area.'*

Despite having her anxieties confirmed and positive action being undertaken, inasmuch as the GUM doctor expediting her Colposcopy referral, further uncertainty and anxiety still awaited:

*'During the colposcopy it was confirmed that my symptoms aligned with those of cervical cancer and the cells needed to be removed and tested. Here I had the LLETZ procedure and awaited [sic] the agonising 4 weeks for my results to be returned. I phoned the colposcopy clinic to receive my results and the cell had been found to be pre-cancerous CIN3 cells (the stage before cells can potentially become cancerous). I felt relieved, but had a lot of questions unanswered.'*

Claire specifies that the wait for the results was 'agonising', and it is apparent that she took a proactive role in chasing up her results at the clinic by telephone (rather than waiting for notification by letter) and that in the mean time she sought advice online, consulting a professional through the Jo's Trust website:

*'It was at this point that I sought advice from the online ask a medical professional service offered by 'Jo's cervical cancer trust'. I had come across the website from my own online searches and had seen a poster displayed at the hospital. I was bemused at how I could have presented with cervical cancer symptoms, yet not developed cancerous cell growth, and I equally was concerned regarding the cause.'*

Claire's anxieties here – surrounding both disease progression (mentioning the stage before cancer) and her concern surrounding the cause agree with the broad themes identified in the 2012 Kosenko study. She goes on to mention toward the end of her narrative that she has now cleared the disease but that:

*'...a part of me felt a little resentful that the process was so drawn out because of my age and the guidelines... I do remain to feel frustrated by the guidelines that are in place, and I think of the possible outcome had I not persisted to have the symptoms and concern addressed'*

#### 5.7.5. Accessing Resources

Two of the respondents, Jay and Claire, mention accessing various resources, to help them through their periods of uncertainty. Jay's coping strategies were focused on learning and mindfulness techniques, particularly after suffering a panic attack during her biopsy appointment:

*'I decided to research my way to peace' –*

*'I used this time to learn about breathing and meditation – ways of keeping myself calm and reducing stress. I would never allow myself to get so out of control again. I started to discover Buddhism at this point, ways of thinking about things differently & more productively. I've learnt valuable skills for life, thanks, in part, to this whole process.'*

Another positive way in which Jay channelled her need to learn and to cope was in the formation of the social media support group:

*'I found lots of information online, but few support groups; so I decided to set up a support group on Facebook – incorporating education, support & awareness. Here I posted my research findings, started discussions, & talked to other ladies about their experiences...it was a very positive way to navigate throughout the process – just knowing that others have been through similar and been ok etc'*

*'Every week on average, we receive at least twenty new member requests.... It's lovely to see how the group has evolved. There's a real love and respect for others, & members tirelessly repeat the fruits of their experiences and knowledge, so as to help any other members who might have missed this information in discussions elsewhere. Our members all proactively use the group to help each other.'*

Here, Jay's narrative reiterates findings from the quantitative arm of the study – of the use of online support to help others, share information and experiences and provide emotional support. In her case, the founding of the group was a coping mechanism, but then learning from other's experiences provided reassurance that the process could be 'navigated'.

This narrative reiterates data presented by LaCoursiere (2001) who outlines a model of social support, and research by various authors who argue that individuals benefit from online social capital through emotional support, information exchange and reassurance by learning about the lived diagnostic and treatment experiences of others (Namkoong et al. 2016; Yoo et al. 2014; Himmelboim & Han 2014; Hersh 2012; van Uden-Kraan 2009, 2008; Beaudoin & Tao 2008, 2007).

Claire also briefly mentions using the social capital derived from her experience to encourage her friends to participate in screening:

*'Since having the 'all clear' I feel that I can talk more openly about my experience and because most of my friends are at the age where they will begin being invited for smear tests, I find myself reassuring them of the process and explaining how important it is to attend.'*

Jo also briefly mentions posting with regard to cervical screening:

*'I posted online re: cervical screening and feel very lucky and passionate about it.'*

Claire's methods of coping involved taking action, either with health professionals to chase appointments of results, or consulting them online to educate herself about HPV:

*'I took it upon myself to do some online research...'*

*'During this wait I spoke to my GP over the phone and asked about the possibility of having smear test. I thought that this would alleviate some of my worry by at least being able to confirm whether the symptoms were caused by cell change.'*

*'A few weeks later I attended a walk-in GUM clinic.'*

*'I phoned the colposcopy clinic to received my results...'*

*'It was at this point that I sought advice from the online ask a medical professional offered by 'Jo's cervical cancer trust'*

Claire coped with the uncertainty and the waiting by taking action through online research, contacting her GP, seeking a second opinion and contacting a health professional online. It is possible that her actions during this time would have been different if she had not had to push quite so hard to be referred in the first place – as if having to push to be referred set the tone of her actions for the remainder of her treatment journey. All of the actions described above – from learning about ways to control anxiety through breathing and meditation, to researching online to contacting health professionals – constitute the mobilisation of resources (internal and external) to find ways of meeting the disruption that the uncertainty and waiting brought to their lives.

#### 5.7.6. Latency

The remaining thread within the theme of uncertainty is that of HPV dormancy or latency. This is mentioned in the biomedical literature as one of the ‘known unknowns’ of HPV positivity (Maglennon 2012; Gravitt et al. 2011; de Witte et al. 2007; Stubenrauch & Laimins 1999). Such knowledge is filtering down to the general public. The Jo’s Trust website has a question dedicated to the topic on its ‘FAQs’ page (Jo’s Trust FAQs 2017). Both Claire and Jay mention the possibility that the virus may reactivate or return:

*‘From my own online research and my contact with Jo’s cervical cancer trust I understand that it is not yet known whether my body will have completely eradicated HPV, or whether it will lie dormant- dependent on the strength of my immune system to fight it off’ - Claire*

*‘I am aware that HPV could return so I’ve learnt how to build my immune system & how to eat myself to the best possible health... If the HPV ever did come back, which I sincerely hope it will not, I would least be better equipped at dealing with it a second time.’ - Jay*

The uncertainty surrounding HPV negativity – and confusion over whether it is due to viral clearance ('being cured') or due to viral dormancy/latency (as means of evading the immune system) can be interpreted as analogous to the fears of recurrence among cancer survivors (Fardell et al. 2016; Freeman-Gibb et al. 2016; Bellizzi et a. 2008; Park et al. 2008; Humphris et al. 2003) which represent biographical and lifecourse disruption (Koutri & Avdi 2016; Salamonsen et al. 2016; Liamputtong & Suwankhong 2015; Little et al. 1998) due to intrusive thoughts. Immediately upon reporting that she is aware of the possibility of HPV dormancy, Claire states:

*'I will never take good health for granted. Most days something triggers my thoughts to return to how lucky I have been.'*

Similarly, Jo states that a bad day is '*one filled with anxiety*' although she does not specifically state that this is due to thoughts of HPV recurrence.

### *Theme 3: Stigma*

#### *5.7.7. Stigma and Self-Stigma*

The final theme that occurred in all the narratives was that of stigma, which was referenced in all three narratives. Previous research studies have demonstrated, many times, that stigma is a recurring factor in the lived experiences of women with HPV (Waller et al. 2007; McCaffery et al. 2006), and stigma was mentioned by all three participants. Jay briefly mentioned that she '*felt mortified*', but this quote was given in recollection of the possibility that she might have had cervical cancer, rather than HPV. HPV is a fairly late entry in Jay's

narrative, not occurring until the last third of her interview. She does mention that she is aware of the stigma surrounding HPV:

*'I've found it particularly interesting how differently HPV is perceived around the world. We have alot [sic] of American's [sic] on the group &, [sic] sadly see alot [sic] of HPV dating websites creep up. HPV is so stigmatised there. I've lost count of how many time [sic] I've told people that HPV is a very common set of viruses, & that most people are exposed to them at some point in their lives. The condition isn't as stigmatised here.'*

Jay does not mention stigma or negative emotions connected with an HPV diagnosis in reference to herself; although she reports awareness of the stigma. However, she also reports awareness of the relative prevalence of the virus, and of the relative risk of exposure to the virus. Jay's awareness of these facts may have helped her to reduce the impact of stigma on her own life. In both Claire and Jo's narratives stigma is internalised, with an acceptance of the negative stereotypes mistakenly attributed to women with HPV. Both mentioned that their lifestyle choices did not fit with the common assumptions about women with HPV (Nack 2002). Claire's first reaction to the news of HPV positivity was puzzlement – *'this created more questions'* as she had received the vaccination and also:

*'...was a non-smoker with a fairly healthy lifestyle, had not had sexual intercourse at a young age and had a very low number of sexual partners'.*

Claire's words indicate her awareness of both the risk factors for contracting HPV (not being vaccinated, early onset of sexual activity, multiple partners – (Franco et al. 1999)), the risk factors for persistent HPV infection/malignant transformation such as smoking – (Park et al. 2008; Sarian et al. 2004) but also the factors that are perceived to contravene acceptable social norms for women – such as multiple sexual partners and early onset of sexarche (Forster et al. 2010; Hilton et al. 2010; Collins et al 2008; Herek 2007), social norms that she is clear in stating she did not break. Jo was also very clear in specifying that, in regard to HPV:



*'I thought it was very common for those whom had several sexual partners. Personally this was not the case for me.'*

Thus although not specifically mentioning the stigma of HPV, both Claire and Jo exhibit self-stigma in pointing out that they did not fit the commonly ascribed social model of sexual behaviour among females reporting positivity for STDs/HPV. These reports were in keeping with the responses specified by women interviewed by Nack in her 2000 and 2002 papers examining the stigma of HPV positivity. In addition, Claire reports that she did not initially disclose the likely cause of her dysplasia to her partner:

*'Interestingly I found myself not wanting to inform my partner of all the details of my treatment at the time –he knew the basics. But I never mentioned the likely cause being HPV until I had digested the information myself. I have since discussed it with him and talk more openly about it with him now.'*

Claire mentions that she did not disclose the full details of the situation to her partner as *'I didn't want to cause any unnecessary worry to anyone else.'*; but her hesitancy in disclosing the cause (HPV) could be interpreted as 'covering' –reducing the effect of one's stigma by controlling the information surrounding that stigma (Goffman 1990b, p.102).

## **5.8. Themes Informing Practice**

As the study formed the largest part of a research degree for a professional doctorate, it was important that the researcher identify themes that might point to knowledge gaps in practice or areas of practice or the service itself that might be improved.

### *Theme 4: Interaction with Healthcare Professionals*

All three women report mixed experiences at the hands of healthcare professionals, both positive, helpful encounters and more frustrating or negative encounters.

### 5.8.1. Negative Encounters with Healthcare Practitioners

Perhaps the most prolonged of these is Claire's story. Claire reports that she visited her GP on 'a few occasions' worried about her symptoms and was asked to return if they returned. In addition she contacted her GP to request a cervical screening test but was refused on the basis of her age. Whilst the GP was correct in refusing her a smear for symptoms and due to her age, Claire felt that her healthcare needs were ignored, and growing increasingly frustrated with the wait and once referred, the waiting list, eventually sought help from another healthcare practitioner at a walk-in clinic. Under NHSCSP guidelines, any woman reporting symptoms associated with cervical cancer (abnormal bleeding patterns such as post-coital or inter-menstrual bleeding or pain during intercourse) should be referred to Colposcopy for further investigation, irrespective of age (NHSCSP, 2016a). Claire's referral should have been made by her GP at the first appointment when she reported symptoms and her appointment at Colposcopy should have occurred within six weeks of her referral (NHSCSP, 2016b)

Jay reports that the punch biopsy procedure was very painful, and that her Consultant was not very helpful in making the experience less stressful:

*'The Consultant asked me to cough but that didn't help at all. I also felt that he was quite rough with me. I had a panic attack on the table... I went home crying & wondering whether I would be able to continue with the process.'*

Although neither of the women reported enacted stigma during their encounters – as described by participants in the Kosenko study (2012), the actions of healthcare professionals during these encounters were not encouraging of questions or helpful in reducing the stress of the situation.

### 5.8.2. Positive Encounters with Healthcare Professionals

However in addition to difficult or challenging encounters with healthcare professionals, participants also reported finding humour or support in both face-to-face encounters with healthcare professionals and in virtual encounters. Jay reports that during her second appointment:

*'...I had also been practising my breathing & meditation leading up to this appointment. I giggled when the Nurse asked the Consultant what size electrical loop wire he needed when he replied "small".'*

She also reports that the Nurse praised her composure during the second appointment:

*'The Nurse commented, after the procedure on how good my breathing technique was throughout, how she wished all ladies could be so calm & well prepared.'*

Claire also reports a positive experience with a healthcare professional, albeit an online interaction following many frustrating encounters with her own GP:

*'I felt relieved, but had a lot of questions unanswered. It was at this point that I sought advice from the online ask a medical professional service offered by 'Jo's Cervical Cancer Trust'. I had come across the website from my own online searches and had seen a poster displayed at the hospital. I was bemused at how I could have presented with cervical cancer symptoms, yet not have developed a cancerous growth, and equally I was concerned regarding the cause. This was the most valuable information I received throughout my whole experience. My questions were answered thoroughly and it was here that I realised the likelihood of my cell change was a result of having HPV.'*

### 5.8.3. Failure to Follow Protocols

One major theme that was identified in two of the narratives surrounded best practice, and the correct following of standard protocols. In Jay's narrative, she reports that she was told:

*'When I did hear back that the biopsy looked fine, I was very relieved; only to be quickly over shadowed by the news that I'd need the LLETZ procedure.'*

Whilst it is possible that Jay was mistaken, or had misinterpreted her biopsy result, in clinical terms, these two events – a negative biopsy ('looked fine') and a LLETZ procedure are mutually exclusive. According to the NHSCSP treatment algorithms, if Jay's biopsy 'looked fine', there would be no clinical need for a LLETZ procedure and waste clinic time and resources and risk further panic attacks (as reported by Jay) on the examination table. As a LLETZ procedure was required, according to the treatment guidelines (NHSCSP 2016a) Jay must have demonstrated a lesion of CIN2 or greater on the biopsy – this does not correlate to 'fine'. Either way, the end result to Jay was confusion.

In addition to Jay's experience, the long fight that Claire had to undertake in order to get referred to Colposcopy (a process of repeated visits and 'watchful waiting' ending in Claire expediting the process by attending a walk-in GUM clinic where a macroscopically visible cervical lesion was discovered) was unnecessary. Again, as noted in the NHSCSP practice guidelines (2010) any woman reporting abnormal symptoms of the type Claire was reporting should be referred to Colposcopy. A routine referral should be seen within six weeks, according the NHSCSP KC65 key performance indicators (NHSCSP 2010a).

### **5.9. Reflexivity and Reflections - Chasing Respondents**

Although interviews were conducted online, and lacked face-to-face features such as non-verbal or behavioural cues that might indicate distress, these aspects of interaction were, nevertheless, often appreciable throughout the research process. For some of the participants who consented to take part, it was possible to identify them in support groups as their contact

details matched the names/profiles they used in online groups, and from comments, questions or statuses posted to groups the researcher was made aware that data collection periods coincided with recall letters from healthcare practitioners, the anxious wait for results or the confirmation of unwanted news – such as continued HPV-positivity or the progression of cervical disease. The perception of these lived-experiences did affect decisions to ‘push for’ or ‘chase’ responses to questions posed in email interviews. As it was obvious that the participants were distressed by their experiences, it did not seem ethical to chase the participants for their email interviews at the risk increasing their anxiety. This (often daily) awareness of participants’ distress – despite a lack of face-to-face interaction – was one of the most difficult aspects of the research process to cope with.

#### **5.10. Conclusions**

The aims for study 2 included were to recruit a population of women from online support resources to participate in qualitative interviews, and to analyse the transcripts of these interviews to document the ways in which women interacted with online support in order to answer the research questions given in section 5.1.2 which asked if a diagnosis of HPV, or HPV and CIN represent a biographical disruption, what factors contribute to this biographical disruption and the role(s) that online support played in the management of that disruption.

In order to answer these questions, seven women were recruited to participate in qualitative research interviews and went through the consent process. Of these seven women, only three responded to the initial email, and returned material for inclusion in the study. These women all opted for or requested asynchronous, electronic interviews – this method of

interviewing, and the data returned by the women are both accepted as limitations to the study (which will be discussed in the next section).

From the data returned by the women, several themes were drawn from their narratives. Theme 1 concerned anxiety derived from information provision including fears surrounding the development of cancer and the provision of 'too much information', variation in information quality, and conflicting information. Theme 2 surrounded uncertainty, including the wait for results or action on the part of healthcare professionals, the development of coping strategies to manage the anxiety aroused by uncertainty, and the possibility of HPV recurrence or reactivation. Theme 3 focused on stigma – all of the women were aware of the stigma surrounding HPV positivity, and 2 made reference to themselves in terms of self-stigma, feeling the need to explain to the researcher that their lives and behaviours did not fit the negative social behaviours commonly associated with the acquisition of an STI.

In order to examine whether the experiences narrated by the women amounted to a disruption to biography, it is sensible to revisit the terms described by Bury in his model of disrupted biography. In his writing, Bury describes a 'creeping onset of symptoms' which lead to the accommodation of changes to 'taken-for-granted assumptions and behaviours', profound disruptions in the explanatory systems used by people including a fundamental rethinking of the self, and a response to disruption through the mobilisation of resources to meet these changes. In Chapter 2, the argument was put forward that due to its asymptomatic nature, HPV did not show the 'creeping onset' of symptoms described by Bury in his writings about chronic diseases such as arthritis. In their narratives, Jay nor Jo reported symptoms that warranted further investigation, but Claire did, and it was her insistence and struggle to get her symptoms recognised and acted on that informed much of her story. Jay and Jo both reported anxiety over fears of developing cancer, which amount to a fundamental rethinking

of the assumption of the self as a healthy individual. In addition, the narration of self-stigma by Claire and Jo indicate that an assessment of the self against the assumed negative social behaviours associated with positivity for an STI has taken place. Perhaps the most telling argument for the process as a disruption to biography is the 'mobilisation of resources' used by the women to cope with the changes and uncertainty they were experiencing: Jay decided to '*research her way to peace*', focused on internal resources – learning anxiety management techniques through breathing and meditation and mobilising external resources by founding a support group as she felt that none existed at the time to meet her needs. Claire's 'mobilisation of resources' included researching her symptoms online, pushing her GP to take a smear, getting a second opinion from a walk-in GUM clinic, chasing the results of her biopsy and asking for explanations from online healthcare professionals. From the narration of these experiences and actions it is possible to argue that their diagnostic experiences constituted a disruption to biography, and that online resources were used to manage the anxiety that disruption caused, through obtaining information (in Claire and Jo's case) to soliciting support from similarly placed individuals by founding a support group in Jay's case.

## Chapter 6 – Conclusions and Discussion

### 6.1. *Conclusions*

This research set out to investigate the notion of HPV as a biographical disruption, and the role that online support might play in the management of that disruption, in anticipation of the move by PHE to implement primary screening of women at increased risk of cervical cancer through the detection of HPV nucleic acids, as by this method, more women were likely to test positive HPV than are currently diagnosed with CIN (Kjaer et al. 2008). The research questions reflected these concerns, asking:

- Does a diagnosis of HPV, or HPV and CIN represent a biographical disruption?
- If either diagnosis constitutes a biographical disruption, what factors contribute to this?
- What roles might online resources play in the management of possible biographical disruption?

In order to answer these questions, a mixed-methods research project was devised, formed of two studies. Study 1 was a questionnaire study delivered online via SurveyMonkey™ to a group of women subscribing to HPV-related online resources gathering quantitative data. Study 2 was a qualitative interview study using online asynchronous email interviews to obtain narrative data about women's experiences of being diagnosed with HPV.

#### 6.1.1. *Outcomes for Study 1*

Study 1 measured perceived stress scores (PSS, Cohen et al. 1983) and social support scores (Sarason et al. 1985) against a number of questionnaire variables such as anxiety over HPV positivity, reasons for anxiety, uses of online support (in terms of emotional support,



exchanging information, helping others and sharing experiences) and outcomes of online support use (in terms of being better informed about HPV and/or gaining better acceptance of HPV). The main outcomes of this study indicated:

- That anxiety over HPV positivity was significantly associated with reduced mean scores for social support (availability and satisfaction) and increased mean scores for perceived stress.
- Reasons given for HPV positivity anxiety included fear of developing cancer, cancer recurrence, stigma and disclosure.
- Free text entries (N =10) of reasons for anxiety over HPV positivity included transmission to partners and children and anticipation of stigma.
- Social support scores as a predictor of disclosure were not found to be significant.
- The uses of online support (for emotional support, exchanging information, helping others and sharing experiences) were associated with increased scores for social support, but these relationships were not significant.

#### *6.1.2. Outcomes for Study 2*

Study 2 was composed of a series of asynchronous, electronic interviews conducted by email asking women to narrate their experiences of HPV positivity and to derive themes from this data. Several themes were identified within the data:

- Anxiety over information (too much information, conflicting information, quality of information)
- Uncertainty (waiting, accessing resources to deal with uncertainty, latency)
- Stigma and Self-Stigma

## ***6.2.Examining Study Outcomes Against the Model of Biographical Disruption***

In reference to the research questions, do any of these outcomes represent a biographical disruption? In his writings, Bury (1991, 1982) described three points to his model of illness as a biographical disruption:

- Changes to taken-for-granted assumptions and behaviours;
- Profound disruptions in the explanatory systems used by people, including a fundamental rethinking of biography and self-concept;
- A response to disruption through the mobilisation of resources

### *6.2.1. Changes to Taken-for-Granted Assumptions and Behaviours*

In study 1 women reported anxiety over HPV positivity in terms of their fears of cancer recurrence (indicating that they had already faced cancer) or cancer development. These fears demonstrate changes to their assumptions of a cure (in the case of cancer recurrence) or the assumption of health (in the case of cancer development). In addition, in the free-text responses, women reported anxiety over transmission to partners (through intercourse) and in one case transmission to children (through sharing drinks). Again, these fears represent changes to taken-for-granted behaviours. Sexual intercourse with a partner, or the sharing of

household items (such as drinks, towels or bedlinen) are now not just normal occurrences that form part of loving relationships but become imbued with the risk of adversely affecting a loved one's health and wellbeing through unintended transmission of the virus.

#### 6.2.2. *Profound Rethinking of the Self*

Again, in study 1, women reported fears of cancer recurrence – these fears threaten the thoughts of self as cured and whole (Brotto & Heiman 2007; Burbie & Polinsky 1992). Fears of cancer development prompt the rethinking of self as a putative cancer patient. In addition, women reported fears around stigma and disclosure, prompting a reassessment of the self as a stigmatised individual. These fears were echoed in the theme of stigma apparent in Study 2, where two of the participants demonstrated self-stigma in the narration of commonly held assumptions of women with HPV. The act of holding themselves as exceptions to these assumptions indicates an assessment of the self against those assumptions, which may not have occurred if they had tested negative for HPV or had not demonstrated cervical abnormalities. However, not all of these reassessments are negative, as one participant in study 2 stated *'Not so much my diagnosis, but my experience, has made me feel as though I have become a more resilient person.'*

#### 6.2.3. *Mobilisation of Resources as a Response to Disruption*

Within the context of this research, the disruption to self may be caused by factors other than the creeping onset of symptoms Bury describes in his writing. Disruption may be caused by the sudden notification of an abnormal cervical cytology result (Rajaram et al.

1998), or an HPV positive result. Within study 1, this disruption can be seen in the indication of anxieties over HPV positivity – in the anxiety over possible recurrent or developing cancer, in the anxiety over stigma and disclosure, and in the anxiety over transmission to others. Within study 2, disruption did have physical or external consequences – Jay describes the pain of her treatment and the cessation of physical activities (*'I had to go on bed rest'*). In addition, Jo believed that her cervical abnormalities arose from the mismanagement of her miscarriage – a profound event in anyone's life course, a loss described in itself as a biographical disruption by Davidson & Letherby (2014); and Claire also reported physical symptoms. However, in addition to these physical causes, the waiting (for referral in Claire's case and for results of biopsies and treatment in Jay's case) and the anxiety about a possible cancer diagnosis represent disruption. In study 1, the demonstration of a mobilisation of resources to meet this disruption was not explicitly explored as a question, but can be seen as an outcome in terms of social support as a resource (Hobfoll et al. 1990). The group of women who reported a lack of anxiety over HPV positivity demonstrated significantly higher mean scores for perceived availability of and satisfaction with social support and lower mean scores for perceived stress than women who reported being anxious about HPV. Within study 2, a mobilisation of resources was more explicitly narrated and drawn upon as a theme within the qualitative data – Jay mobilised 'internal' resources, stating that she: *'decided to research [her] way to peace'* by obtaining information online, starting a support group and managing stress and anxiety by teaching herself meditation, breathing exercises and learning about Buddhism. She also accessed physical resources by consulting her GP for medication to manage her anxiety on the day of her Colposcopy appointment. Claire also narrates a process of accessing resources – presenting at her GP (with symptoms), undertaking online research, getting a second opinion through attending a walk-in clinic to obtain a referral to Colposcopy and by seeking advice from the 'Ask a Professional' service on the Jo's Trust website.

#### 6.2.4. Factors Contributing to Biographical Disruption

The outcomes for each study were examined to explore the factors that contributed to disruption. Both studies specifically mention anxiety – in study 1 this was a researcher-led question ('Please indicate your level of anxiety over a possible HPV positive test result') but with the majority of the population (N = 79, 73.8%) indicating they were anxious. Examination of the reasons for anxiety identified fears of the recurrence or development of cancer, anxiety surrounding stigma and disclosure, and anxiety surrounding transmission to partners and loved ones. Responses from study 2 echoed these findings, with anxiety being identified as one of the overall themes, related to the provision of information – either too much information, conflicting information or information of variable quality. Anxiety over cancer development was mentioned by all three participants in the qualitative study, with Jay wondering if she had *'just been told I had cancer?'*, Jo reporting on her experiences of the Jo's Trust website that *'having the word 'cancer' all over the pages is very daunting and scary'* and Claire becoming aware through online research that her symptoms *'resembled those of cervical cancer'*. Anxiety over stigma in study 1 was the third most commonly selected response to the question 'If you were anxious about HPV, what form would these fears take?' and being mentioned in the free-text responses by one participant as *'people's knowledge and assumptions'*, although when asked if they would disclose a positive HPV test result, the majority of women (N =94, 87.9%) indicating that they would disclose. In study 2, Jay acknowledged the stigma surrounding HPV, and Claire mentions hesitation in telling her partner of the role of HPV in cervical abnormalities. Jo states her assumption that [HPV] *'was very common for those whom had several sexual partners. Personally this was not the case for me.'* Claire was also clear that she had avoided stigmatised behaviours and risk factors such as smoking, early sexarche and sexual promiscuity. In addition to fears surrounding cancer and

stigma, the concept of uncertainty either as diagnostic uncertainty or life-course 'trajectory uncertainty' occurring as a result of an unlooked-for diagnosis constitute a disruption to biography (Williams 2000).

#### *6.2.5. The Role of Online Support in Managing Biographical Disruption*

The final research question asked what role online support might play in the management of a biographical disruption such as that which persistent HPV positivity might represent. In order to answer this question, it is important to recap the issues that HPV positivity represents. Much has been made of the stigmatised nature of HPV, and the anxiety surrounding both the threat to identity and the threat to health (in the form of neoplasia) that it represents. It is in managing the threats to identity and physical health that online support may facilitate the management of HPV positivity as a biographical disruption. Cavanagh (2007, p.109) describes community (in the virtual space) as 'a shorthand for common forms of social identity', therefore the threat to identity may be managed by joining an online groups – virtual communities composed of Goffman's "Own", 'virtual communities of care' (Chambers 2006, p.120) where the reconstruction of self-identity may be facilitated by the recognition of the self amongst peers. In addition to renegotiating identity, women may turn to online support for other purposes. Setoyama et al. (2011) compared face-to-face support groups with online support groups among women with breast cancer, and found that both groups used peer support for advice, emotional expression, emotional support and helper therapy. Within Study 1, women were asked to indicate their agreement with statements of uses for online support; specifically for: emotional support, exchanging information, helping others and sharing experiences. Women who agreed with the statement 'I use online support for emotional

support' reported the lower mean scores for social support availability than women who disagreed with the statement (although this relationship was not statistically significant). These women may be using online support as an adjunct resource if the emotional support provided by other channels was not as available as they would have wanted.

On the basis of the findings in the quantitative data (particularly the responses to question 20 – fears surrounding HPV positivity), and themes uncovered in the free-text responses and the narrative supplied by women through online interviews, it is possible to conclude that due to the associated anxiety, uncertainty and stigma, HPV positivity represents a biographical disruption; and that the use of online support to share experiences, exchange information and help others represents a means of negotiating a path around that disruption, helping to resolve it.

### **6.3. *Validity of Data and Interpretation***

It is important to remember that the philosophical underpinnings of the study and the role of the researcher are both interpretative. To aid reflection and interpretation summary notes were made immediately upon receipt of both communication emails and the responses to interview questions. Additionally, notes/journal entries of reflection and self-reflection were kept throughout the research project to facilitate the identification of assumptions. As interviews were not conducted face-to-face, the researcher did not get the opportunity to guide the interview in specific directions, and participants had the opportunity to prioritise the questions and issues that were important to them. However, as the role of the researcher is interpretative, the results of the study 'research reflect the researcher as much as the researched' (Salmon, 2003, p.27).

Bearing this in mind, the researcher took pains to separate the original, verbatim accounts and the interpretations drawn there from, as recommended by Smith & Osborn (2003). These are included in Appendices 10, 11 and 12 in order that the reader can draw their own conclusions from the text, and assess the accuracy of the researcher's interpretation. Reid *et al.* (2005) suggest that independent readings of transcripts by multiple researchers may be effective in developing a joint thematic framework, and that these analyses could further be checked by other academics – these measures could be utilised as a form of cross-validation; however, time constraints and the solitary nature of a research degree meant that these measures were not possible in the case of this study. Original verbatim accounts and researcher interpretations were seen by and discussed with the doctoral supervisor in order to perform a check on these interpretations.

#### *6.3.1. Reliability/Generalisability*

Yardley (2000) argues that as the purpose of qualitative research is to offer one of many interpretations of the data, and therefore reliability may not be an appropriate criterion against which to measure data analysis. Reflecting on the research process and data gleaned, and bearing in mind the vociferous criticisms of Paley in the application of Heideggerian research in healthcare, the study does not and cannot make claims of generalisability to an entire screening population on the basis of a small questionnaire sample and the narrative accounts of three individuals. The sample population for the questionnaire study was too small to reliably allow generalisability to the UK screening population. In addition, from the perspective of the qualitative data, thematic analysis is inductive, so the researcher was able to examine the data in the context of current issues in the field of HPV screening and public



health, to highlight the lack of account being taken for the sociological and psychological burden this change to the screening method represents, and to make recommendations for both further study and future practice.

#### **6.4. *Implications of Findings***

Having explored the interactions between online support group use and the psychosocial impact of HPV/cervical cancer, the author asks how the findings can be used. Again, with the criticisms of Paley (2016; 2014; 1996) in mind, it would be unwise to generalise to an entire population, but the researcher can still use the findings to inform practice within her department and make recommendations to PHE for further research to further explore issues uncovered. These include:

- Examine departmental protocols to ensure that NHSCSP referral guidelines are followed, and reiterate these to primary care providers in training sessions
- Encourage the use of standardised letters with the researchers Colposcopy department to prevent the possibility of conflicting information
- Pass on findings of the study to PHE, and recommend further research into the subject of online support and informational needs of HPV affected women.

##### **6.4.1. *Actions on Study Findings***

The researcher provides training to sample-takers (practice nurses) and primary care (GPs) throughout the Leicester, Northants and Rutlands region (although this is subject to

change under the proposed regional reconfigurations that the HPV primary screening implementation project demands). Training documentation will be updated to include information/research findings on transmission to partners and children, through day-to-day living (such as the likelihood of transmission through sharing drinks or bedlinen) including the likelihood of perinatal transmission for the counselling of pregnant patients who test HPV positive during screening (Thomas, 2001) – even if the advice is to do nothing – in order to reassure women raising concerns about transmission via means other than sexual transmission. Training documentation will be updated to highlight the value (either as online support or for healthcare information gathering) of signposting reliable, evidence-based online HPV-related resources such as NHS Choices and Jo’s Trust, and to highlight the difference between online support (emotional support and sharing experience) and online clinical advice. In her role as liaison to local Colposcopy departments documentation for invitation letters (for biopsy/treatment appointments and follow-up discharge letters) and local treatment policies will be reviewed to ensure that information given is clear and that treatment algorithms are followed.

The researcher will contact PHE with the findings of the study to highlight the need for updated information for patients to be included in the preparation of documentation for the implementation of HPV primary screening. PHE is now the publisher of the NHSCSP documentation, and the researcher will highlight the need for further information on ‘living with HPV’ to be included in the next version NHSCSP Good Practice Guide.

#### *6.4.2. Public Awareness: Reduction/Elimination of Stigma*

The findings of this study agree with previous research – HPV still attracts stigma. The findings of Study 1 indicated that of a population of HPV positive women who indicated an awareness of HPV (87.9% of the population), only 40 selected the statement that HPV is the most commonly acquired STI in the UK as true. In addition, quotes in Study 2 indicated that two of the respondents, both aspiring healthcare practitioners (nursing students), who by the nature of their training were in the process of acquiring health literacy, and of whom one had been vaccinated (and thus presumably given informed consent) expressed little awareness of the role of HPV in cervical abnormalities prior to their diagnosis. Thus at present, the ubiquity of HPV and the inefficacy of barrier contraceptive in preventing transmission – two factors that might reduce stigma – are little known by the general public; being knowledge that is acquired on a ‘need-to-know’ basis post-diagnosis. At present there is very little publicity or information in the public sphere that attempts to reduce or remove this stigma. Therefore the researcher intends to contact both PHE and other stakeholders (Jo’s Trust) with the study findings in order to highlight the need to publicise more widely the relative lifetime risk of contracting HPV, the limited use of condoms in preventing infection, that individuals of both genders can carry and transmit the virus and that individuals do not have to have penetrative sex to transmit the virus.

#### **6.5. *Limitations of the Study***

The author is an early-career researcher, studying a relatively post-positivist field from a historically positivist standpoint. The author has little experience of building or administering

questionnaires, hence the long iterative phase of development of the research instrument. The author is aware of some of the major limitations of the study which are listed as follows:

- Relatively small sample size
- Lack of validated measures for some aspects of the survey
- Reliance on thin data from email interviews
- Lack of responses to follow-up questions to email interviews
- Lack of ethnic diversity in the sample/non-English version of questionnaire
- Difficulty in identifying women who were HPV positive only

#### 6.5.1. *Sample Size*

Study 1 recruited just over 100 people to the questionnaire arm (N = 107) and 3 individuals to the e-mail interview phase. For a quantitative study, a sample size of N =100 is very small, and whilst statistical significance was indicated in one relationship between variables, this finding may change when explored with a larger sample. The data was therefore used as an exploratory study to examine the reasons women might subscribe to HPV related online support. The sample size has implications for generalisability as well as for statistical power – as such it would not be responsible to generalise the findings to the entire UK screening population without further study. Sample sizes for the interview study were similarly small. The only difficulty with a small interview sample was the identification of themes. In order to report themes within the research, a ‘theme’ was so called when more than one individual reported or made reference to it.

### *6.5.2 Lack of Validated Measures in the Questionnaire Study*

The majority of areas of the questionnaire instrument used validated measures – the demographic section used questions from the UK Census and the data for the dependent measures was gathered using validated measures – the SSQ-6 and the PSS-10. However, the questions used to indicate anxiety and embarrassment did not use validated measures such as Stait-Trait Anxiety or the Internalised Shame Scale, instead using Likert scales for women to indicate their level of anxiety of embarrassment. In addition, the Likert scale for anxiety conflated the states of anxiety and worry, which are measured as two separate entities in psychological studies. This may have caused confusion among respondents which may in turn have affected their responses.

### *6.5.3. Reliance on Thin Data from Electronic Interviews*

Originally the qualitative aspect of the study was designed with FtF interviewing in mind, as this is the gold-standard method for obtaining thick descriptive data. However, all of the participants requested to undertake interview by email. This did allow the participants to answer the questions they felt were relevant to them, but also meant that the data returned was thin, and returned at a time suitable to the participant. In addition, follow-up questions asking for further information or clarification on specific answers (such as Jo's statement that her miscarriage caused her cervical abnormalities) were ignored. The lack of responses to follow-up emails may be due to a difficulty in establishing rapport via email. Both Claire and Jo were recruited to the study via Jo's Cervical Cancer Trust, therefore the researcher did not have to opportunity to establish rapport via social media, as was the case with Jay.

Another challenge in relying on data derived from email interviews were the issues of trustworthiness and authenticity. The use of email interviews does not allow for the observation of non-verbal cues such as facial expression, non-verbal vocalisations, pauses or body language which may give clues to giving 'trustworthy' responses. In addition, the asynchronicity of email allows the participant time to consider their response and self-edit to allow a more socially desirable response. Hine (2000, p.118) states that the domain of the Internet has provided 'new problems in judging what is authentic'. James & Busher (2007) also highlight this issue, but posit that allowing the participant to dictate the pace of the interaction (in their case over several weeks) allows the participant ownership of the encounter.

#### *6.5.4. Lack of Ethnic Diversity*

The lack of responses from British Minority Ethnic women is another limitation to the study. Many attempts were made to reach as wide an ethnic audience as possible (within the confines of the internet). The author contacted BME Cancer Voice in order to attempt to recruit individuals from ethnically diverse populations. However, despite contacting several organizations (correspondence is supplied in Appendix 2), no response from or contact with an administrator or group leader could be established. There are several possible explanations for the lack of uptake of/participation in the study. Previous research has indicated that internet use is associated with increased socio-economic status (to allow access to a personal computer and a network connection). Ethnic diversity research would suggest that individuals from BME populations have lower socioeconomic status, and thus possibly less access to the Internet (Mesch & Talmud 2011) (Fogel et al. 2008; Fogel et al. 2003). In addition, no

translations of the questionnaire were made available for individuals who spoke English as an additional language or did not speak English at all. Research suggests that lack of participation due to a language barrier is a significant contributor to poor uptake of internet-based research among BME populations (Im & Chee 2005).

Another significant contributor could be a lack of affect among BME populations – HPV infection and cervical cancer incidence is lower (compared to the national average) in Muslim women, for example (Dutttagupta et al. 2004), although this may be due to lack of reporting, rather lower incidence. Thus women in these populations may have felt that the research did not apply to them and thus chose not to participate in the research. However, the reduced rates of HPV and cervical cancer may not be due to a reduced incidence within the population but from lack of reporting among British Asian women due to a reduced uptake in screening due to the social, language and cultural barriers that may be encountered during a screening appointment. The stigma associated with cervical screening may extend to research via the Internet and it is possible that individuals saw the survey and followed the link but failed to complete the survey or navigated away from the page before completing. As SurveyMonkey™ doesn't count web 'hits' it is impossible to know how many individuals opened the survey versus how many completed it. Attitudes among BME communities towards better acceptance of HPV and cervical disease (for men as well as women) is a topic that would benefit from further research of this type.

#### *6.5.5. Effects of HPV positivity vs. Effects of CIN*

During the recruitment phase, it was not possible during this study to identify any women who had tested HPV positive without an accompanying diagnosis of CIN (of any grade)

that had not been followed up by biopsy and excisional treatment. However, questionnaire data demonstrated a small subsection of women who had tested positive but who had not required treatment. Both the structure of the questions in the survey and in the interview schedule specifically makes reference to the effects and meanings of HPV positivity on the lived experience of affected women rather than CIN.

#### **6.6. *Dissemination of Findings***

From a professional perspective, as an application to practice, the results of this study will be communicated to Public Health England in order to facilitate strategic planning for the move to HPV primary screening, to highlight the information needs of the screening population and refine the information that is disseminated prior to testing (with the invitation letter) and for any information that accompanies result letters. In addition, the author hopes to publish the findings of the project in a reputable journal associated with the field (such as the Journal of Biomedical Science, Social Science and Medicine, and Patient Education & Counselling) and in reputable journals associated with the method of data collection (Telemedicine and Health Informatics). In tandem with liaison with PHE and journal publication, the author hopes to produce a poster to display at the biennial conference for the Institute of Biomedical Science, the National Association of Cytologists and the British Society for Colposcopy and Cervical Pathology.



### **6.7. Further research**

Some of the suggestions for further research are mediated by the suggestions for contacting Public Health England with the study findings as described in section 6.4. These research suggestions include contacting PHE to establish an electronic survey to be distributed to healthcare practitioners (GPs, Colposcopists, Gynaecologists, Nurse Colposcopists, Practice Nurses and Health Visitors) to examine the most commonly asked questions that patients ask in clinic about living with HPV/transmission to partners and children in order to examine knowledge gaps among both patients and healthcare practitioners, in order to inform further training. Despite contributing to the body of knowledge on the subject of HPV, particularly the role of the Internet in mediating anxiety following diagnosis, many questions remain unanswered within the context of the screening programme. Further research might answer these questions. If the focus of the screening programme shifts to HPV primary screening rather than cervical cytology, then Public Health England may consider extending both screening and vaccination to males as well as females in order to reduce the likelihood of a healthcare inequality and to remove the possibility of gender-blaming (Brankovic et al. 2013). In preparation for HPV primary screening (whether female-specific or for both genders) the attitudes and opinions of men should be canvassed (via Internet-based research) to examine whether use of online support groups might benefit HPV-positive individuals or the relatives of HPV-positive individuals.

The response to online support in British Minority Ethnic populations still remains largely unanswered. Low responses to the questionnaire have been examined earlier in this chapter, but identifying specific groups within the BME population to establish whether their information and support needs are currently being met by physical or online provisions should be a matter of priority. A matched pairs study of individuals who access the internet and those

who rely on physical support and face-to-face communication could be undertaken to examine whether the effects of computer-mediated communication are comparable to those of women who use face-to-face communication. In addition, a repeated measures study or matched pairs study of women in the process of HPV screening or cervical cancer diagnosis/treatment/follow-up could be undertaken to examine whether better information (regarding ubiquity of the infection, effects on fertility and expectations of the treatment process) may reduce the stigma and attributional responsibility of HPV infection.

A comparative analysis of stigma in vaccinated and non-vaccinated HPV positive individuals in the age cohort who have been routinely offered vaccination might be undertaken to examine whether a 'two-tier' stigma exists – whether non-vaccinated HPV positive individuals feel doubly stigmatised.

#### **6.8. *Conflicts of Interest***

No conflicts of interest have been identified. The author has not received any financial or other incentive from any of the charities mentioned or examined as part of this research (Jo's Trust, the Teal Ladies, Macmillan or the British Society for Colposcopy or Cervical Pathology). No financial or other incentives were received by the author from SurveyMonkey™. Costs of the SurveyMonkey™ survey (an annual subscription at a cost of £250) were met by the Health and Life Sciences Faculty of De Montfort University – the account is a departmental one, rather than a personal account set up for the author. The author continues to work as a Biomedical Scientist Team Leader at Kettering General Hospital NHS Foundation Trust which did not make any financial contribution to the completion of this project. All work was completed outside of employment hours (evenings and weekends) or

taken as annual leave. The author's place on the DHSci programme at De Montfort University was in part sponsored by the Learning Beyond Registration contract by the Healthcare Workforce Development Federation, for which the author gives her sincere thanks.

### **6.9. *Reflections on Practice Development***

The process of studying for the Doctorate in Health Science has definitely had a profound effect on the author's practice. At the beginning of the programme, the taught phase of the programme definitely highlighted the authors' previous practice of biomedical science for a very positivist perspective – the formation of a hypothesis, the testing of a hypothesis, the collation of data and the drawing of a conclusion. The original project, and indeed, this study, were designed from a positivist perspective and dealt almost exclusively with the gathering of quantitative data to test a hypothesis. However, the research methods and philosophies modules in the early part of the programme allowed learning and appreciation of post-positivist research paradigms and their application to the author's practice.

Both this study and the author's field of practice stand at and awkward crossroads of research and scientific philosophies. Biomedical science is largely a 'hard' science, relying on statistical data to predict or monitor health outcomes. However, within the field, the discipline of cytology is based on the visual appreciation of microscopic appearances, pattern recognition and to some extent, gut instinct. Cytology results can be quantified statistically, as specificities and sensitivities, but the degree of malignancy with a nucleus, cannot, within the context of the slide being examined at the time. Instead, the cytologist relies on qualitative 'data' obtained from the slide – physical appearances, the presence of bacteria, inflammatory

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cells and other pathogens. It thus seemed quite appropriate (on the failure of the author's first project) to have moved from a project based on the quantitative analysis of nucleic acids to a more qualitative research field – if not in the nature of the data, then in the over-arching ethos of the research concept, in the examination of the qualitative aspects of life following a diagnosis of cervical cancer or HPV. The move to a relatively new field has definitely aided the author's development both as a researcher and as a practitioner in Cytology. The author is now definitely more aware of applying a label to an individual which they might then have to live with or bear the memory of for the remainder of their lives. The consequences of diagnosis as seen at Colposcopy multi-disciplinary team meeting and at invasive cancer audit meetings and patient liaison are more profound to the author, particularly since the data collection period began and the qualitative narratives were obtained.

#### **6.10. *Claims of Originality***

This study makes a claim to original knowledge based on three factors: on the basis of professional practice, as the first time a biomedical scientist has undertaken a medical sociology project using online recruitment methods to better understand the HPV positivity, to provide information to improve practice and policy. Second, this is (to date) the first piece of research has examined the use of social media in the support of HPV positivity. In addition, it is the first study that demonstrates that the notion of HPV dormancy has reached the public consciousness as reported by participants in the qualitative arm of the study. This knowledge should be built on through the provision of further research in the area of online social support, with a view to better publicising online support provision to women in the advent of HPV primary screening implementation.

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## Appendices

## Appendices

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**Appendix 1: Original Ethical Approval Document for Questionnaire Study**



HLS FREC Ref: 1179

12<sup>th</sup> December 2013

Jessica Leads  
Kettering General Hospital

Dear Jessica,

**Re: Ethics application – A Quantum of Solace: The effect of online information gathering and social media use on perceived stress following a positive diagnosis of human papillomavirus (HPV). (Ref: 1179)**

I am writing regarding your application for ethical approval for a research project titled to the above project. This project has been reviewed in accordance with the Operational Procedures for De Montfort University Faculty of Health and Life Sciences Research Ethics Committee. These procedures are available from the Faculty Research and Commercial Office upon your request.

I am pleased to inform you that ethical approval has been granted by Chair's Action for your application. This will be reported at the next Faculty Research Committee, which is being held on 30<sup>th</sup> January 2014.

Should there be any amendments to the research methods or persons involved with this project you must notify the Chair of the Faculty Research Ethics Committee immediately in writing. Serious or adverse events related to the conduct of the study need to be reported immediately to your Supervisor and the Chair of this Committee.

The Faculty Research Ethics Committee should be notified by e-mail to [HLSFRO@dmu.ac.uk](mailto:HLSFRO@dmu.ac.uk) when your research project has been completed.

Yours sincerely,

A handwritten signature in blue ink that reads "M. Grootveld".

Professor Martin Grootveld  
Chair  
Faculty of Health and Life Sciences  
Research Ethics Committee

## ***Appendix 2: Text of Questionnaire Document***

### Introduction, Patient Information and Consent

The purpose of this study is to examine the use of the internet in managing stress in women following a diagnosis of human papillomavirus (HPV), the virus associated with cervical cancer. This research is being undertaken by a research student at De Montfort University as partial fulfillment of a Doctorate in Health Science.

Your participation in this research is voluntary. You may choose not to participate, or you may withdraw at any time by closing the browser window. If you decide not to participate, or decide to withdraw, this will not affect any treatment you are currently undergoing, or waiting for. The procedure involved filling in an online survey, which takes about 20 minutes to complete.

Your responses are anonymous and confidential. Identifying information such as your name, email or IP address is NOT collected. The survey is made up of several sections, asking questions about your age, ethnicity, relationship and education status; your HPV/cervical screening history and knowledge; your internet usage and two short measures of perceived stress and perceived social support. If you consent to participate, this means that you give permission for the researcher to use your anonymous responses in the study, to analyse these responses, and to publish the results or papers based on the results of these analyses. You cannot be identified by your responses.

#### Contact Information

If you have any questions or complaints about this study please contact:

Dr G Basten/Dr S Oldroyd

Hawthorn Building, De Montfort University, The Gateway, Leicester, LE1 9BH

Or contact: 0116 250 6070

and ask for Dr S Oldroyd, Head of Health & Life Sciences regarding the HPV Social Media Study

#### Privacy, Anonymity and Confidentiality

Whilst your information is confidential at the point of collection, you may wish that the topic of this research (HPV) is kept private from family and friends. It is therefore recommended that you clear your browser history after you have completed the questionnaire or withdrawn from the study. Your privacy is protected as your identity including your email address, is hidden from the researcher. You are anonymous.

Your privacy is protected as your identity; including your email address will not be known or identified in the publication of any results. Your privacy is protected as all your responses are anonymous - your personal responses may be shared with the research supervisor or published in a research article, but you will not be identifiable by your responses to the questionnaire.

Your personal information cannot be sold, exchanged or given to a third party as it is not known to the researcher. Participation in this study will not pose any risk to your health or wellbeing, nor affect any treatment you may be having. Responses to this questionnaire are automatically encrypted.

### Benefits/Disadvantages

What are the potential disadvantages of participating in this study?

The questions in this research may cause you to worry. This research is not intended or designed to cause you harm, either physically or psychologically. If the contents of this questionnaire upset you or cause you worry, you may wish to contact your GP for advice. In addition, you may find the following sources of information helpful:

[www.cancerscreening.org.uk](http://www.cancerscreening.org.uk)

[www.jostrust.org.uk](http://www.jostrust.org.uk)

[www.macmillan.org.uk](http://www.macmillan.org.uk)

[www.samaritans.org](http://www.samaritans.org)

[www.relate.org.uk](http://www.relate.org.uk)

What are the possible advantages of participating in this study?

You may learn more about HPV, whether or not you have the condition. This knowledge may provide you with reassurance about the virus, or the knowledge and skills to comfort a family member or friend who may have HPV.



## DEMOGRAPHIC DATA

### 1 Please indicate your age

#### Age Range

18-24

25-34

35-44

45-54

55-64

65-74

#### Reason for Question

Do age ranges follow screening programme demographics. Older age brackets not eligible for screening but may still be on ten year follow-up under old system. Originally going to be a freetext box, but Professor Jin recommended categories.

### 2 Relationship status

Single

Long term relationship  
/marriage/civil partnership

Divorced

Widowed

Marital status might influence whether and to whom volunteer confides in/asks advice of

### 3 Ethnicity

White/British

White/Other

Indian

Pakistani

White/Irish

Mixed

Black Caribbean

Black African

Bangladeshi

Chinese

Other Asian (Non-Chinese)

Black (Other)

Other

Prefer not to say

Possible health inequality exists re: uptake of screening/health literacy/access to internet/health advice.

### 4 Residential status

Alone

Live with parents/family

Live with friends/housemates

Living with partner

Residential status might influence whether and to whom volunteer confides in/asks advice of

### 5 Employment status

Employed 37+ hrs per wk

Employed <37hrs per wk

Unemployed, seeking work

Unemployed, not seeking work

Again, may affect social support - support by colleagues? Unemployed, not seeking work (e.g. full time mums) may not have access to support from colleagues/managers, or may indicate more support

Retired due to confiding in other mums?  
Disabled, not able to work May affect perceived stress.

**6 Awareness of HPV**

Are you aware of the human papillomavirus (HPV)

Yes

No

Gauge level of awareness within the population

**7 HPV anxiety**

Please indicate your level of anxiety over an HPV positive result

Very worried/anxious

Worried/anxious

Neither worried nor unconcerned

Likert scale

Not worried/anxious

Really not worried/anxious

Prefer not to answer

**8 Shame/embarrassment over HPV**

Please indicate your level of embarrassment at a positive HPV result.

Very embarrassed

Embarrassed

Neither embarrassed nor unembarrassed

Not embarrassed

Really not embarrassed

**9 Do you have daughters eligible for the HPV vaccine**

Yes

No

**10 HPV Testing History**

Have you ever had an HPV test?

No I am not in the screening programme

No, I choose not to participate

No I have not been HPV tested

I don't know

Yes I have had an HPV test

Prefer not to answer

**11 Screening Frequency**

Please indicate how often you participate in cervical screening.

Never I choose not to participate

Never, not been invited yet

Occasionally - I don't always go when I receive my invitation letter

Regularly - when I receive my invitation

Frequently, I arrange for additional screening

Frequently, I am being managed by my local hospital following previous treatment

## 12 Screening History

Have you ever had an abnormal smear result?

An abnormal result includes any of the following:

Borderline, mild or low-grade dyskaryosis; moderate, severe or high-grade dyskaryosis, ?invasive cancer, ?glandular abnormality or result codes 3, 4, 5, 6, 7 or 8; or result letters B, E or M.

No, I have never been screened

No I have never had an abnormal result

Yes, I have had an abnormal result

I don't know

Prefer not to say

## 13 Treatment History

Have you ever been offered or undergone treatment for an abnormal r?

I have an appointment but have not attended yet

I have been to hospital and had a biopsy

I have been to hospital and had treatment (a LLETZ, cone biopsy, cold coagulation or laser on)

I have received treatment and had a follow-up test

I have not required treatment

Prefer not to say

## 14 HPV Knowledge Measure

Please select the statements you believe to be true

HPV is a sexually transmitted infection

HPV is the most common sexually transmitted infection in the UK

HPV may go away on its own

HPV may not produce any outward signs or symptoms

HPV may cause cervical cancer

HPV transmission may not be not stopped by condoms

**15 HPV Knowledge Source**

How did you find out about HPV

From my doctor

From nurses/other staff at the surgery/clinic

From doing research on the internet for myself

From doing research on the HPV vaccine for my daughters

From family/friends/partner(s)/colleagues

From NHS Direct

Prefer not to answer

**16 Disclosure**

Would you confide in anyone over a positive HPV result

Yes

No

Prefer not to say

**17 Whom would you speak to?**

My partner

Family member(s)

Friend(s)

A doctor or nurse

An online support group

Prefer not to say

**18 If you were anxious about a positive HPV result what form would your worries take?**

Please select all that apply:

Disclosure - telling my partner, family, friends or colleagues

Fertility - how HPV will affect this

Health - I am worried about developing cancer

Health - I am worried about cancer returning

Life - I am scared of dying

None of the above - I am not concerned

Other (please specify) [freetext response up to 1000 characters]

**19 Do you use the Internet to look up healthcare information**

No I would use other ways to research healthcare information

I sometimes use the internet to look up healthcare information

I frequently use the internet to look up healthcare information

**20 Would you use the internet to look up advice/information or reassurance on HPV**

No I have never thought of using the internet for this kind of support

Yes I would use the Internet to seek advice/reassurance if I could remain anonymous

Yes, I use the Internet to seek advice, information and reassurance on various aspects of my life

his would be no different.

- 21 Which of the following resources have you heard of
- NHS Direct
  - NHS Cancer Screening (Website)
  - Jo's Trust (Website)
  - British Society for Colposcopy and Cervical Pathology
- 22 How often do you log into internet forums or online support groups
- Less than a few times a month
  - A few times a month
  - A few times a week
  - About once a day
  - More than once a day
- 23 How long have you been using an HPV-related online support group
- I don't use them
  - A few weeks
  - A few months
  - About a year
  - Over a year
  - Prefer not to say
- 24 If you use online support groups, when did you last post on a forum or message board.
- I don't use them
  - I don't post, I just read
  - I've posted in the last week
  - I've posted in the last month
  - I've posted in the last few weeks
  - I've posted in the last few months
  - I've posted in the last year
  - Prefer not to say
- 25 Please indicate your agreement with the following statement:  
"I use social media or online support groups for exchanging information."
- Strongly disagree
  - Disagree
  - Neither agree nor disagree
  - Agree
  - Strongly agree
- 26 Please indicate your agreement with the following statement:

"I use social media or online support groups for emotional support."

Strongly disagree

Disagree

Neither agree nor disagree

Agree

Strongly agree

27 Please indicate your agreement with the following statement:

"I use social media or online support groups to help others."

Strongly disagree

Disagree

Neither agree nor disagree

Agree

Strongly agree

28 Please indicate your agreement with the following statement:

"I use social media or online support groups for sharing experiences."

Strongly disagree

Disagree

Neither agree nor disagree

Agree

Strongly agree

29 Please indicate your agreement with the following statement:

"Since using social media or online support groups I feel better informed about HPV."

Strongly disagree

Disagree

Neither agree nor disagree

Agree

Strongly agree

30 Please indicate your agreement with the following statement:

"Since using social media or online support groups I have better acceptance of HPV."

Strongly disagree

Disagree

Neither agree nor disagree

Agree

Strongly agree

Social Support Questionnaire starts on next page

## Social Support

The following questions are based on the 6-item Social Support Measure (Short-Form). You will be asked to list a number of individuals you feel you can rely on in specific situations (you do not need to name them, you may use nicknames, or initials, or titles /roles [such as 'brother']). You will then be asked to rate your satisfaction with their support on a scale of 1 to 5.

- 31 Whom can you count on to be dependable when you need help, to listen when you need to talk?

Please list individuals by initials, or by role (e.g. A.T. or 'cousin' or 'best friend' or 'neighbour')

1	6
2	7
3	8
4	9
5	

- 32 Of the people mentioned above, how satisfied are you with the support you receive

Very dissatisfied

Dissatisfied

Neither satisfied nor dissatisfied

Satisfied

Very satisfied

- 33 Whom can you really count on to help you feel more relaxed when you are under pressure or

Please list individuals by initials, or by role (e.g. A.T. or 'cousin' or 'best friend' or 'neighbour')

1	6
2	7
3	8
4	9
5	

- 34 Of the people mentioned above, how satisfied are you with the support you receive

Very dissatisfied

Dissatisfied

Neither satisfied nor dissatisfied

Satisfied

Very satisfied

- 35 Who accepts you totally, including your best and worst points?

1	6
2	7
3	8
4	9
5	

36 Of the people mentioned above, how satisfied are you with the support you receive

Very dissatisfied

Dissatisfied

Neither satisfied nor dissatisfied

Satisfied

Very satisfied

37 Whom can you count on to care about you, regardless of what is happening to you?

1 6

2 7

3 8

4 9

5

38 Of the people mentioned above, how satisfied are you with the support you receive

Very dissatisfied

Dissatisfied

Neither satisfied nor dissatisfied

Satisfied

Very satisfied

39 Whom can you count on to help you feel better when you are down in the dumps?

1 6

2 7

3 8

4 9

5

40 Of the people mentioned above, how satisfied are you with the support you receive

Very dissatisfied

Dissatisfied

Neither satisfied nor dissatisfied

Satisfied

Very satisfied

41 Who can you count on to console you when you are very upset

1 6

2 7

3 8



- 42 Of the people mentioned above, how satisfied are you with the support you receive
- Very dissatisfied
  - Dissatisfied
  - Neither satisfied nor dissatisfied
  - Satisfied
  - Very satisfied

#### Perceived stress

The following questions form the Perceived Stress Scale.  
Please read the question and use the scale to identify your response.

- 43 How often have you been upset by something that happened unexpectedly?
- Never
  - Almost never
  - Sometimes
  - Fairly often
  - Very often
- 44 How often have you felt unable to control the important things in your life
- Never
  - Almost never
  - Sometimes
  - Fairly often
  - Very often
- 45 How often have you felt nervous or stressed?
- Never
  - Almost never
  - Sometimes
  - Fairly often
  - Very often
- 46 How often have you felt confident in your ability to handle your problems
- Never
  - Almost never
  - Sometimes
  - Fairly often

Very often

- 47 How often have you felt things were going your way  
Never  
Almost never  
Sometimes  
Fairly often  
Very often
- 48 How often have you felt you could not cope with all the things you had to do  
Never  
Almost never  
Sometimes  
Fairly often  
Very often
- 49 How often have you been able to control irritations in your life  
Never  
Almost never  
Sometimes  
Fairly often  
Very often
- 50 How often have you felt that you were on top of things  
Never  
Almost never  
Sometimes  
Fairly often  
Very often
- 51 How often have you been angered because of things that were outside your control  
Never  
Almost Never  
Sometimes  
Fairly often  
Very often
- 52 How often have you felt difficulties were piling up so high you could not overcome them?  
Never  
Almost Never  
Sometimes  
Fairly often  
Very often



**Appendix 3 – Inferential Statistic Analyses for Questionnaire Study**

ANOVA of mean scores for social support availability (SSQN), social support satisfaction (SSQS) and perceived stress (PSS) against HPV anxiety.

**ANOVA**

			Sum of Squares	df	Mean Square	F	Sig.
SQN	S	Between Groups	13.486	1	13.486	13.813	.000
		Within Groups	82.010	84	.976		
		Total	95.495	85			
SQS	S	Between Groups	11.041	1	11.041	16.160	.000
		Within Groups	57.392	84	.683		
		Total	68.433	85			
SS	P	Between Groups	39.128	1	39.128	6.876	.010
		Within Groups	460.896	81	5.690		
		Total	500.024	82			

Linear Regression of PSS, SSQN and SSQS against Disclosure Intention

**Variables Entered/Removed<sup>a</sup>**

Model	Variables Entered	Variables Removed	Method
1	PSS, SSQS, SSQN <sup>b</sup>	.	Enter

a. Dependent Variable: Would you confide in anyone about a positive HPV result?

b. All requested variables entered.

**Model Summary**

Model	M	R	Adjusted R	Std. Error of the Estimate
		Square	Square	
1		.211 <sup>a</sup>	.044	.008
				.34821

a. Predictors: (Constant), PSS, SSQS, SSQN

### ANOVA<sup>a</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.445	3	.148	1.224	.307 <sup>b</sup>
	Residual	9.579	79	.121		
	Total	10.024	82			

a. Dependent Variable: Would you confide in anyone about a positive HPV result?

b. Predictors: (Constant), PSS, SSQS, SSQN

ANOVA for Embarrassment\*Perceived stress, Social Support Availability & Social Support Satisfaction

			Sum of Squares	df	Mean Square	F	Sig.
SS	P	Between Groups	20.201	2	10.101	1.861	.162
		Within Groups	428.677	79	5.426		
	Total	448.878	81				
SQN	S	Between Groups	4.296	2	2.148	1.401	.251
		Within Groups	157.901	103	1.533		
	Total	162.197	105				
SQS	S	Between Groups	3.367	2	1.684	1.501	.228
		Within Groups	115.551	103	1.122		
	Total	118.919	105				

Multivariate GLM of SSQN, SSQS and PSS for Reasons for Online Support Use  
(emotional support, exchanging information, helping others and sharing experiences) and  
Outcomes of Online Support Use  
(better informed about HPV, better acceptance of HPV)

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.998	1093.913 <sup>b</sup>	1.000	2.000	.001
	Wilks' Lambda	.002	1093.913 <sup>b</sup>	1.000	2.000	.001
	Hotelling's Trace	546.956	1093.913 <sup>b</sup>	1.000	2.000	.001
	Roy's Largest Root	546.956	1093.913 <sup>b</sup>	1.000	2.000	.001
SSQN	Pillai's Trace	.946	1.861 <sup>b</sup>	19.000	2.000	.407
	Wilks' Lambda	.054	1.861 <sup>b</sup>	19.000	2.000	.407
	Hotelling's Trace	17.682	1.861 <sup>b</sup>	19.000	2.000	.407
	Roy's Largest Root	17.682	1.861 <sup>b</sup>	19.000	2.000	.407
SSQS	Pillai's Trace	.928	2.335 <sup>b</sup>	11.000	2.000	.338
	Wilks' Lambda	.072	2.335 <sup>b</sup>	11.000	2.000	.338
	Hotelling's Trace	12.843	2.335 <sup>b</sup>	11.000	2.000	.338
	Roy's Largest Root	12.843	2.335 <sup>b</sup>	11.000	2.000	.338
PSS	Pillai's Trace	.902	1.834 <sup>b</sup>	10.000	2.000	.404
	Wilks' Lambda	.098	1.834 <sup>b</sup>	10.000	2.000	.404
	Hotelling's Trace	9.168	1.834 <sup>b</sup>	10.000	2.000	.404
	Roy's Largest Root	9.168	1.834 <sup>b</sup>	10.000	2.000	.404
SSQN * SSQS	Pillai's Trace	.000	. <sup>b</sup>	.000	.000	.
	Wilks' Lambda	1.000	. <sup>b</sup>	.000	2.000	.
	Hotelling's Trace	.000	. <sup>b</sup>	.000	2.000	.
	Roy's Largest Root	.000	.000 <sup>b</sup>	1.000	1.000	1.000
SSQN * PSS	Pillai's Trace	.631	1.140 <sup>b</sup>	3.000	2.000	.499
	Wilks' Lambda	.369	1.140 <sup>b</sup>	3.000	2.000	.499
	Hotelling's Trace	1.710	1.140 <sup>b</sup>	3.000	2.000	.499
	Roy's Largest Root	1.710	1.140 <sup>b</sup>	3.000	2.000	.499
SSQS * PSS	Pillai's Trace	.000	.000 <sup>b</sup>	1.000	2.000	1.000
	Wilks' Lambda	1.000	.000 <sup>b</sup>	1.000	2.000	1.000
	Hotelling's Trace	.000	.000 <sup>b</sup>	1.000	2.000	1.000
	Roy's Largest Root	.000	.000 <sup>b</sup>	1.000	2.000	1.000
SSQN * SSQS * PSS	Pillai's Trace	.000	. <sup>b</sup>	.000	.000	.
	Wilks' Lambda	1.000	. <sup>b</sup>	.000	2.000	.
	Hotelling's Trace	.000	. <sup>b</sup>	.000	2.000	.
	Roy's Largest Root	.000	.000 <sup>b</sup>	1.000	1.000	1.000

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	Since using OSGs I feel better informed about HPV	39.886 <sup>a</sup>	80	.499	1.994	.392
	Since using OSGs I have better acceptance of HPV	39.663 <sup>b</sup>	80	.496	.	.
Intercept	Since using OSGs I feel better informed about HPV	273.478	1	273.478	1093.913	.001
	Since using OSGs I have better acceptance of HPV	284.519	1	284.519	.	.
SSQN	Since using OSGs I feel better informed about HPV	8.841	19	.465	1.861	.407
	Since using OSGs I have better acceptance of HPV	7.054	19	.371	.	.
SSQS	Since using OSGs I feel better informed about HPV	6.422	11	.584	2.335	.338
	Since using OSGs I have better acceptance of HPV	5.152	11	.468	.	.
PSS	Since using OSGs I feel better informed about HPV	4.584	10	.458	1.834	.404
	Since using OSGs I have better acceptance of HPV	4.833	10	.483	.	.
SSQN * SSQS	Since using OSGs I feel better informed about HPV	.000	0	.	.	.

	Since using OSGs I have better acceptance of HPV	.000	0	.	.	.
SSQN * PSS	Since using OSGs I feel better informed about HPV	.855	3	.285	1.140	.499
	Since using OSGs I have better acceptance of HPV	.484	3	.161	.	.
SSQS * PSS	Since using OSGs I feel better informed about HPV	.000	1	.000	.000	1.000
	Since using OSGs I have better acceptance of HPV	.250	1	.250	.	.
SSQN * SSQS * PSS	Since using OSGs I feel better informed about HPV	.000	0	.	.	.
	Since using OSGs I have better acceptance of HPV	.000	0	.	.	.
Error	Since using OSGs I feel better informed about HPV	.500	2	.250		
	Since using OSGs I have better acceptance of HPV	.000	2	.000		
Total	Since using OSGs I feel better informed about HPV	532.000	83			
	Since using OSGs I have better acceptance of HPV	512.000	83			
Corrected Total	Since using OSGs I feel better informed about HPV	40.386	82			
	Since using OSGs I have better acceptance of HPV	39.663	82			



- a. R Squared = .988 (Adjusted R Squared = .492)
- b. R Squared = 1.000 (Adjusted R Squared = 1.000)

## Appendix 4: Ethical Approval for Amendments to Include Interviews

(Screenshots of email conversation with graduate school office)

FREC Amendments Approved (Ref: 1179) Inbox x DHSci@DMU x 03/11/2016 ★ ↶ ↷

**HLS Faculty Research Ethics Committee** <hlsfro@dmu.ac.uk> to me, Stephen

Dear Jessica  
**Re: Ethical Approval Application –An exploratory mixed-methods study of use of online supports groups in women in human papilloma virus (Ref: 1179)**  
Further to the original approval of the above named project, I can confirm that the Chair of the Faculty Research Ethics Committee has approved the amendment request submitted on **21<sup>st</sup> October 2016**. This will be reported in the next Ethics Committee meeting.

Should there be any further amendments to the research methods or persons involved with this project you must notify the Chair of the Faculty Research Ethics Committee immediately in writing. Serious or adverse events related to the conduct of the study need to be reported immediately to your Supervisor and the Chair of this Committee.

██████████ The Faculty Research Ethics Committee should be notified by e-mail to [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk) when your research project has been completed.

Regards

**Tom Moore**  
Faculty Research Ethics Committee  
Faculty of Health & Life Sciences, De Montfort University  
1.25 Edith Murphy House, The Gateway, Leicester, LE1 9BH  
T: 0116 250 6122 / 0116 257 7775  
Email: [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk)  
Website / forms: <http://www.dmu.ac.uk/research/ethics-and-governance/faculty-specific-procedures/health-and-life-sciences-ethics-procedures.aspx>

## **Appendix 5: Approach Letters to Gatekeepers**

### Approach to Jo's Trust

Dear Madam or Sir,

I am a doctoral research student currently studying at De Montfort University for a Doctorate in Health Science. You may remember that I contacted the Jo's Trust site in 2014 to request that a link to my research was included on your research links page.

I am still studying for the qualification, and as part of revisions to my doctoral thesis I have been requested to undertake some qualitative research to complement the quantitative data that I have already collected. The qualitative aspect of this research involves recruiting participants – subject to informed consent – for a short, digitally audio-recorded, qualitative research interview lasting approximately 1 hour.

A copy of the broad themes and questions to be asked is attached to this email, along with a copy of the research proposal and a letter from the University indicating that ethical approval has been granted for this project.

Checklist:

- Project proposal
- Broad themes
- Informed consent and participant information sheet
- Screenshot of survey monkey electronic consent form

## **Appendix 6: Approach to Social Media Gatekeepers**

Dear Madam or Sir,

I hope you don't mind me contacting you and I hope I haven't alarmed you by contacting you out of the blue.

I am a research student at De Montfort University in Leicester, studying for a Doctorate in Health Science. I am researching the lived-experience of HPV positivity, and the role that online support groups, communities and forums (such as the one you administrate) play for women who are HPV-positive. As you may know, HPV is the virus that causes cervical abnormalities.

I found your group by searching for groups on Facebook related to cervical screening, Colposcopy or HPV, and then by looking up the administrators for each group. It is in the capacity of administrator of such a group that I am contacting you.

Through my research I would like to understand the day-to-day lived experiences, questions and concerns that these women face; and the ways in which groups like this provide support (through reassurance, giving information, or simply by allowing women to know they are not alone).

Would it be acceptable for me to join your group, and to ask if you or your members would be willing to take part in a short interview (this could either be face-to-face, or by email or messenger) about their experiences. I thought it would be more polite to contact you and ask first, rather than just join and starting posting in the group comments.

At present I am only recruiting women to the study, as (at present) only women are tested for HPV through the NHS Cervical Screening Programme. Women must be over 18 years of age and able to read, write and speak English.

My study has been approved by the De Montfort University Research Ethics committee and includes a participant information sheet and informed consent process available online at SurveyMonkey. Details of my study may also be found at the CallForParticipants page on the link below.

You can find my study here: <http://cfp.cc/ZDCK55>

CallForParticipants is a website that allows academic (and non-academic) researchers to set up a webpage giving information about their study.

You can check out the participant information here at SurveyMonkey <https://www.surveymonkey.co.uk/r/3WZWF7M8>

Please be assured that clicking on either of these links does not presume consent. If you are not interested, please just close the tab, page or window.

I can provide copies of my project proposal and ethical approval if you wish.

I hope that my contacting you has not alarmed you or awakened any distressing memories.

Please accept my sincerest apologies if I have done so.

Many thanks for your time,

Jessica

## Appendix 7: Participant Information Sheet



### PARTICIPANT INFORMATION SHEET

**Title of Project:** A study examining the use of online support groups in women with HPV.

**Name of Investigators:** Jessica Leads (Researcher);  
Dr Stephen Handsley (First Supervisor), Dr Graham Basten (Second Supervisor)

#### Invitation paragraph

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and/or relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part or not. Thank you for reading this.

#### What is the study about

The purpose of this study is to recruit female volunteers from HPV-related websites, forums and online support groups, and ask them to participate in a short, face-to-face or online interview to explore how information, advice and support online have helped them with their diagnosis (if at all). The data will be used by the researcher to write a 50,000 word thesis as partial fulfilment of a professional Doctorate in Healthcare Science at De Montfort University.

#### What does the study involve?

You have been invited to participate in a short face-to-face or online interview. This interview will not have a rigid structure; you are free to explore areas of interest surrounding the topic as they arise. The interview will last no longer than one hour. The interview will be recorded on a digital recording device, but care will be taken to ensure that your privacy and anonymity are protected – no names or locations will be used or named during the interview.

Excerpts or quotes from the interview will be quoted in the main body of the text, but no information that may identify you will be used. Neither you nor any one close to you will be named in the transcript or the thesis. Descriptors of your situation may be changed by you (e.g. use of a pseudonym) in order to protect your identity, if you wish.

#### Why have I been chosen?

You have been chosen to take part because you responded to a message posted in an online forum for a site devoted to HPV that asked for volunteers to conduct an interview about their experiences of HPV and of online support.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Taking part in or withdrawing from the study will not affect any healthcare or counselling or treatment that you are receiving.

#### I am interested in taking part, what do I do next?

Contact the researcher at the email address given below.

**What if I agree to take part and then change my mind?**

You can withdraw from the study at any time, without giving a reason. Any data collected up to the point that you decided to withdraw will not be used if you do not wish for it to be used.

**What is the procedure that is being tested?**

You can decide if you want to participate in a face-to-face interview, or to participate in an online interview. If you choose face-to-face, you will meet with the researcher somewhere convenient to you, and reasonably quiet and private, which is not your home. An example might be the local public library or a coffee shop. You will be given another opportunity to read this information sheet and if you wish to continue, you will sign a consent form to indicate this. Once you have consented, you may be asked questions about how you feel about HPV, and how you feel about visiting a website to find information or support. You are encouraged to talk as freely as possible, rather than giving "Yes/No" type answers.

If you wish to participate in an online interview, you can make contact with the researcher at the email address below. You can view your participant information sheet and consent form online, and have the questions emailed to you (if you wish to participate by email), or you can have an interview conversation using a messenger system (such as Facebook messenger).

**What are the possible disadvantages and risks of taking part?**

The interview topic is a sensitive and emotive subject, and has the potential to cause you distress. If you feel upset and wish to continue, the interview will be paused so you can gather yourself if you wish. If you do not wish to continue, the interview will cease, and you can withdraw.

**What are the possible benefits of taking part?**

There are no direct benefits to you, although there is a possibility that you may find talking anonymously about your experiences may help you in some way. Your interview and the research may not include direct benefit to you, and may not benefit you personally but will provide information which will inform teaching for practice nurses or healthcare professionals as to how to help women with HPV. Participation or non-participation will not affect any access to any treatment you may currently be receiving.

**What if something goes wrong? / Who can I complain to?**

Complaints concerning anything to do with this study should be first addressed to the researcher at the email address given on page 3 (in "Contacts for Further Information"). If you feel that your complaint has not been appropriately handled by the researcher, you can contact the University Ethics committee at the address and email given below:

Administrator for the Faculty Research Ethics Committee,  
Research & Commercial Office,  
Faculty of Health & Life Sciences,  
1.25 Edith Murphy House,  
De Montfort University,  
The Gateway, Leicester, LE1 9BH or email: [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept on a password protected database and is strictly confidential. You will be given an ID code which will be used instead of your name. Any identifiable information you may give will be removed and anonymised. All data from this study (interview transcripts and consent forms) will be kept securely for 5 years (after the completion of the study), and then destroyed in a confidential manner.

The supervisor will also have access to the data and members of the human research ethics committee may require access to check that the study has been conducted in accordance with the approval. As before, all data is anonymous, so even if the supervisory team or ethics committee view it, they will not know that the data was from your interview.

You should also be aware that I may be duty bound to pass on information that you provide that reveals harm has occurred to a child or other vulnerable individual.

#### What will happen to the results of the research study?

The results of this research – in the form of quotes and transcripts will form part of a 50,000 word thesis submitted as partial fulfilment of a research degree – a Professional Doctorate in Health Science from De Montfort University. Once accepted (after corrections) the thesis will be available in the university archives to view on request by students at De Montfort University library. In addition, at a later date, anonymised quotes from your interview may be included in the production of an article for a reputable journal in a relevant subject area (examples as health psychology, cyber psychology or medical screening journals).

#### Who is organising and funding the research?

The degree programme that this study forms a part of is funded by the National Health Service "Learning Beyond Registration" Workforce Development team. The actual study (researcher's time and travel, provision of digital recorder, provision of information leaflets and consent forms) is self-funded by the researcher – no external, commercial or professional bodies or organisations have provided any monies toward research.

#### Time or travel expenses

Unfortunately, the researcher is unable to pay you for your time during the interview or to reimburse any travel expenses incurred getting to the interview. There are no financial incentives to participation. No gifts, rewards (such as store or gift cards) or discounts for any products can be offered in exchange for participation.

#### Who has reviewed the study?

This study has been reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee.

#### Contacts for Further Information

	Researcher	Supervisor
Name	Miss Jessica Leads	Dr Stephen Handsley
Email	<a href="mailto:PO8143070@my365.dmu.ac.uk">PO8143070@my365.dmu.ac.uk</a>	<a href="mailto:shandsley@dmu.ac.uk">shandsley@dmu.ac.uk</a>
Address	C/O Dr S Handsley 3.29 Edith Murphy House De Montfort University The Gateway, Leicester LE1 9BH	Dr S Handsley 3.29 Edith Murphy House De Montfort University The Gateway, Leicester LE1 9BH

#### Useful Contacts

Relate	<a href="http://www.relate.org.uk">www.relate.org.uk</a>	0300 100 1234
Jo's Trust	<a href="http://www.jostrust.org.uk">www.jostrust.org.uk</a>	0207 250 8311
The Samaritans	<a href="mailto:jo@samaritans.org">jo@samaritans.org</a>	116 123
NHS Choices	<a href="http://www.nhs.uk">www.nhs.uk</a>	111
The Patient's Association	<a href="mailto:helpline@patients-association.com">helpline@patients-association.com</a>	0208 423 8999
The Eve Appeal	<a href="http://www.eveappeal.org.uk">www.eveappeal.org.uk</a>	0207 605 0100
Cancer Research	<a href="http://www.cancerresearch.uk">www.cancerresearch.uk</a>	





Thank you for taking part in this study



## CONSENT FORM

**Title of project:** Qualitative Research Interviews for HPV Online Support

**Name of researcher:**

Please initial all boxes if you agree

1. I confirm that I have read and understood the information sheet [October 2016, version 1.0] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I agree that non identifiable quotes may be published in articles or used in conference presentations.
4. I agree to the interview being digitally audio recorded
5. I understand that data collected during the study may be looked at by a supervisor from De Montfort University. I give permission for the supervisor to have access to my data.
6. I agree to take part in this study

\_\_\_\_\_  
Print name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Print name of person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Consent form date of issue: [October, 2015]

Consent form version number: [Version 1]

Appendix 8: Interview Schedule

THEME TO EXPLORE	TYPE OF QUESTION						
	DESCRIPTIVE	NARRATIVE	STRUCTURAL	CONTRAST	EVALUATIVE	CIRCULAR	COMPARATIVE
Meaning making: Feelings surrounding diagnosis/diagnostic process	Can you describe how you felt after you were diagnosed	Can you tell me how you came to your diagnosis (letter/face to face appointment)	So what stages were involved in the diagnostic or treatment process	Can you tell me what you thought about HPV before your diagnosis? How does it differ from your thoughts now?	Can you tell me what your diagnosis means to you?	If you could go back – what advice would you give to yourself about hearing the news for the first time?	
Biographical work – The Self	How would you describe yourself as a person?		Has your outlook or your role changed since your diagnosis?	Has your diagnosis changed the way you think about yourself?	Do you feel you are a different person – since diagnosis/ since getting the all- clear?	Overall, has this been a positive or a negative experience in your life?	
Daily Life	Can you describe a typical day?		Do you plan days or events around how you are feeling?	Can you tell me about a good day, and a bad day?			

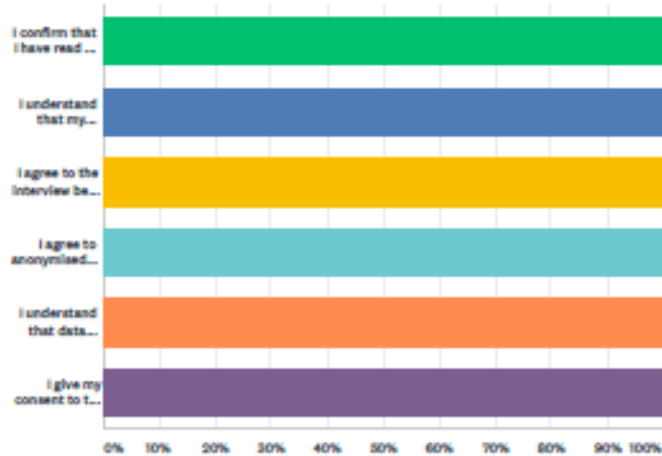
**Appendix 8: Interview Schedule (continued)**

	TYPE OF QUESTION							
THEME TO EXPLORE	DESCRIPTIVE	NARRATIVE	STRUCTURAL	CONTRAST	EVALUATIVE	CIRCULAR	COMPARATIVE	
Support	<p>Can you tell me about a time when HPV came up in conversation with a partner/friend/family member?</p> <p>Do you post online, or do you just read – can you explain why you just read?</p> <p>Can you tell me about your first online post?</p>		<p>What was the process of getting involved with online support?</p> <p>How did you become an advisor administrator</p> <p>Do you plan posts or questions in advance, or do you respond to what you see/read?</p>			<p>How do you feel after conversations about it?</p> <p>How do you feel after forum visit?</p> <p>How do you feel after you’ve posted</p>		<p>Do you feel you get different information or support from a particular group, say, your physical friends or your online friends?</p>
Relationships	<p>Can you tell me how your diagnosis affects your relationships with partner/family friends</p>		<p>Can you tell me where you fit in your relationships?</p>			<p>How do you think other people see you?</p> <p>Has your role changed since your diagnosis?</p>		

## Appendix 9: Record of Informed Consent for Interviews

**Q6 Informed consent** Please read and tick the following statements in relation to the information you have read, and to indicate that you consent to an interview.

Answered: 7 Skipped: 0



ANSWER CHOICES	RESPONSES
I confirm that I have read and understood the participant information for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	100.00% 7
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	100.00% 7
I agree to the interview being digitally audio recorded (if conducted face-to-face).	100.00% 7
I agree to anonymised messages being copied into Word if conducted online by email.	100.00% 7
I understand that data collected during the study may be looked at by a supervisor from De Montfort University. I give permission for the supervisor to have access to my anonymised data.	100.00% 7
I give my consent to take part in this study.	100.00% 7
<b>Total Respondents: 7</b>	

Categorize as...  Filter by Category

Search responses

Showing 7 responses

<input type="checkbox"/> [Redacted] .uk	5/16/2017 12:01 PM	<a href="#">View respondent's answers</a>	<a href="#">Categorize as...</a>
<input type="checkbox"/> [Redacted] .et.com	4/29/2017 10:33 PM	<a href="#">View respondent's answers</a>	<a href="#">Categorize as...</a>
<input type="checkbox"/> [Redacted] h@gmail.com	4/15/2017 6:38 PM	<a href="#">View respondent's answers</a>	<a href="#">Categorize as...</a>
<input type="checkbox"/> [Redacted] m	3/11/2017 12:43 AM	<a href="#">View respondent's answers</a>	<a href="#">Categorize as...</a>
<input type="checkbox"/> [Redacted] .ill.com	3/6/2017 4:57 PM	<a href="#">View respondent's answers</a>	<a href="#">Categorize as...</a>
<input type="checkbox"/> n [Redacted] .uk			

**Appendix 10: Jay's Narrative**

Question Response	Researcher interpretation	Practitioner interpretation Notes on the process/practice points that should have been followed
<p>How did you learn about your diagnosis?  <i>During January 2011, after a routine pap smear test, I received a letter stating that I would need to see a Consultant because abnormalities on my cervix had been found – which I later learnt was CIN 2 &amp; 3. Along with this letter was a cervical cancer leaflet. At first I felt mortified, had I just been told that I had cancer? I re-read the letter a few more times &amp; read the leaflet, &amp; then realised that cervical cancer was a possible outcome. I have very mixed views on this. Would it perhaps have been more appropriate to hand out such a leaflet, if needed, later in the process? On the other hand, handing out such a leaflet at this early stage may help some ladies to realise the gravity of their situation; &amp; thus, they are more likely to go through with Colposcopy, biopsy &amp; LLETZ procedures. So I feel quite conflicted about the usefulness of the literature – at such an early point anyway. In my case, I felt, it added to my stress &amp; anxiety levels. Even though I had rationalised in my head that it was being issued to prepare me, just in case; given the wait times between appointment &amp; results, &amp; the months involved, the possible cancer diagnosis hung over me like a dark cloud.</i></p> <p><i>I had hear about HPV prior to this date, however I didn't know much about it. After receiving this letter, I decided to research my way to peace.</i></p>	<p><i>'Mortification – embarrassment?' Confusion.</i></p> <p><i>Already self-reflecting. More confusion?</i></p> <p><i>Swamped with information?</i>  <i>Does leaflet lead to catastrophising?</i></p> <p><i>Differential perspectives – early in diagnostic process, but disease is already significantly advanced – Goffman's invisible stigma</i>  <i>Conflict, over level of information, type of information</i>  <i>Being informed added to stress/anxiety.</i>  <i>Rationalisation</i>  <i>Waiting</i></p> <p><i>"Hung over me like a dark cloud"</i></p> <p><i>Minimal knowledge of HPV – follow up on</i></p>	<p><i>Diagnosed before HPV triage/TOC came in.</i>  <i>What was grade of abnormality – must have been high grade to go straight to Colp.</i></p> <p><i>Are we frightening patients by trying to give them all the information at once – different responsibilities – trying to inform vs. trying to protect peace of mind as long as possible?</i>  <i>Want people to be treated, but not out of fear.</i></p> <p><i>Does the literature need reviewing – Delphi technique type focus groups?</i>  <i>How long was wait for results – staffing in our histology lab is low – we don't have enough consultant to report cases. This is a nationwide issue. Colposcopy clinics cannot keep up with demand, because referrals are up 20% since triage/TOC came in. Need more clinics, more Ob/Gyn consultants and nurses, more lab staff and pathologists.</i></p>

<p><i>I found lots of information online but few support groups; so I decided to set up a support group on Facebook – incorporating education, support &amp; awareness. Here I posted my research findings, started discussions, &amp; talked to other ladies about their experiences. Some opinions caused me anxiety, e.g. how painful certain procedures are, &amp; other opinions put my mind to rest. But by &amp; large it was a very positive way to navigate throughout the process – just knowing that others have been through similar &amp; have been ok etc.</i></p>	<p><i>how she knew. Letter was prompt toward personal research. Knowledge = peace.</i></p> <p><i>Sharing experiences can be as confusing as formal leaflet-based information. Anxiety over pain. Positivity through shared experience.</i></p>	<p><i>Should PHE work more closely with charities and support groups to signpost incoming patients to support procedures?</i></p>
<p><i>So, going back to the diagnostic process, my first appointment with the Consultant was about a month later – seemed like a lifetime. I can't recall if the first appointment was a sit down and talk assessment, or if I went straight to Colposcopy &amp; biopsy. But I do remember the Colposcopy &amp; biopsy well. I found the punch biopsy part very painful. The Consultant asked me to cough but that didn't help at all. I also felt he was quite rough with me. I had a panic attack on the table. My husband, who was allowed to sit with me, tried his best to calm me – bless him. I went home crying &amp; wondering whether I would be able to continue with the process. Just to add more context, at the point, I had been diagnosed with M.E. following a prolonged illness due to the Epstein-Barr virus. So I was already very unwell.</i></p> <p><i>Again, there was a wait of about 3–4 weeks before I heard anything more – a very scary wait. I used this time to learn about breathing and meditation – ways of keeping calm &amp; reducing stress. I would never allow myself to get so out of control again. I started to discover Buddhism at this point, ways of thinking about things differently &amp; more productively. I've learnt valuable skills for life, thanks, in part, to this whole process.</i></p>	<p><i>Waiting. 'Seemed like a lifetime'</i></p> <p><i>Pain. Not a helpful/supportive diagnostic encounter.</i></p> <p><i>Support. Appreciation of supportive relationship.</i></p> <p><i>Anxiety at being able to continue/cope with pain. What outcomes were.</i></p> <p><i>Multiple co-morbidities.</i></p> <p><i>Waiting. Fear.</i></p> <p><i>Proactive. Learning coping techniques. Control – over process? Over body? Already been diagnosed with other illnesses, so very</i></p>	

<p><i>When I did finally hear back that the biopsy looked fine, I was very relieved; only to be quickly overshadowed by the news that I'd need the LLETZ procedure. Again, another fling into the unknown. At this point, my support group had quickly grown in numbers. I was able to discuss the procedure in a private forum – as it is a closed group – meaning people can post without friends or family seeing their postings in their newsfeed. (I know I value my privacy on such matters. And I know others on the group do also). Some women said the procedure hardly hurt &amp; they were able to go back to work the next day, others stated that it made them poorly for a few weeks. Bearing in mind that few ladies I spoke to found the biopsy painful, I wondered how the LLETZ would compare.</i></p> <p><i>I took myself off to my GP &amp; asked if he could give me anything for the day to help me manage my stress &amp; anxiety levels. I explained what happened on biopsy day &amp; that I've been learning some breathing exercises etc. He gave me Diazepam.</i></p> <p><i>My LLETZ took place about a month after I received my results. I definitely felt more relaxed that day – possibly because of the Diazepam – but I had also been practising my breathing &amp; meditation leading up to this appointment. I giggled when the Nurse asked the Consultant what size electrical wire loop he needed when he replied “small”. As the procedure took place, I did my special breathing that kept me really calm, &amp; I had my wonderful husband at my side again, which really helped too. They numbed my cervix with a local anaesthetic this time – unlike during the biopsy &amp; Colposcopy. (Looking back, I think a local anaesthetic should actually be offered for the biopsy &amp; Colposcopy too). The</i></p>	<p><i>little control over the ill self? Some positive outcomes. Skills. Coping strategies. Gratitude?</i></p> <p><i>Relief. Conflicting information. ‘Overshadowed’ – couple of references to dark/shadows/cloud now. ‘Fling’ literally Heidegger’s “thrownness”. Unknown, not knowing, angst. Private group – fear of disclosure/reluctance to disclose/Goffman’s ‘the wise’ Privacy Comparing lived experiences. Self-comparison.</i></p> <p><i>Self-reflection</i></p> <p><i>‘Took myself off to GP’ – mobilisation of resources? Empowerment – actively seeking solutions. ‘biopsy day’ – definitely an event in her life. Breathing/coping exercises</i></p> <p><i>Think she means results of the Bx. Mobilisation of resources – breathing and medication.</i></p> <p><i>Managed to find humour in the situation.</i></p>	<p><i>Who on earth gave this information?! If the biopsy was fine, there would be no need for a LLETZ. So conflicting information being given – if this is the opposite scenario to the leaflet (e.g. trying to reassure/drip feed bad news as opposed to preparing the patient for the worst), this was the worst possible way it could have been done “you’re fine, but you need a deeper, more invasive treatment”. Really bad point of practice.</i></p> <p><i>GP doesn’t know what drugs are going to be administered during procedure. If the respondent had to have a GA the Diazepam might have made prescribing very difficult during the procedure. Midazolam and/or Diazepam are often prescribed as sedatives during the procedure – she might have ended up with an overdose.</i></p>
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<p><i>Nurse commented, after the procedure on how goof my breathing technique was throughout, how she wishes all ladies could be so calm &amp; well prepared, &amp; that I could teach my breathing technique to others. That felt good. I had worked very hard to keep my composure – through teach yourself breathing &amp; meditation. Funnily enough, my husband &amp; I laughed afterward that we could smell bacon during the procedure. It's very true! :OD From what I've learnt about the procedure, they burn away a certain amount of layers of the cervix.</i></p>	<p><i>Supportive partner</i></p> <p><i>Recommendations on future practice.</i></p> <p><i>Teaching/empowering others.</i></p> <p><i>Humour. Using emojis – helps convey emotion in absence of FTF cues.</i></p> <p><i>Research into procedure.</i></p> <p><i>'The cervix' – not 'my cervix' – distancing from Rx/damage?</i></p>	
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**Appendix 11: Claire's Narrative**

Question Response	Researcher interpretation	Practitioner interpretation Notes on the process/practice points that should have been followed
<p>stages were involved in the diagnostic or treatment process? agnosis process was somewhat different to the norm, mainly se I was age 22 and not entitled to a smear test. ented at the GP on a few occasions with some abnormal ptoms; I was advised to monitor them and return if they ued. They did continue and I was then referred to Colposcopy outine measure. At this point the nurse mentioned that it be down to 'abnormal cells'. it upon myself to do some online research regarding my ptoms and I was aware my symptoms resembled those of al cancer.</p> <p>ymptoms and my worry continued, as did the waiting list for ospital appointment. During this wait I spoke to my GP over hone and asked about the possibility of having a smear test. I ht that this would alleviate some of my worry by at least able to confirm whether the symptoms were caused by cell e.</p> <p>ver, the GP informed me that due to NHS guidelines, I was igible to have a smear because of my age.</p>	<p>Awareness of difference</p> <p>Awareness of abnormal symptoms</p> <p>Awareness of abnormal symptoms Why? Not enough information from nurse? 'Took it upon myself' – empowerment? Control? First use of online health information seeking 'My symptoms' – ownership? First mention of 'cancer'.</p> <p>Anxiety. Waiting. Frustration?</p> <p>Active health seeking behaviour. Reassurance.</p> <p>'At least' – almost pleading. Level of desperation. Knowing/confirmation vs. current state of uncertainty 'Cell change' – health literate – occurs after her mention of research; so, learned, not told.</p>	<p>Underage for screening Should have been referred straight away</p> <p>This shouldn't have been a 'routine' referral. This should have been an urgent referral.</p> <p>She should have been referred on a 'two week wait' at her first GP appointment.</p> <p>The GP was correct, and a smear would not have altered her treatment pathway/clinical outcome, but it might have saved her the wait.</p>

<p>weeks later I attended a walk-in GUM clinic as my concerns symptoms were ongoing. I was hoping to rule out any infection may be causing my issues. Here, the doctor informed me that an internal examination he could see an abnormal area.</p>	<p><i>Frustration? Denied healthcare when in need? Denied reassurance. Denied a sense of control</i></p> <p><i>Taking control. Stigma of attending GUM clinic, initially? Use of abbreviations – specialist language. Ongoing worry, illness, otherness of body 'Hoping' for an infection = desperation. Infection - ?first inkling of HPV? 'An abnormal area' = otherness, not me. Not: 'my cervix looked abnormal' Goffman's deformity of the body (even if not visible to others, you know now)</i></p>	<p><i>If her GP/practice nurse had examined her at her first appointment (irrespective of a smear test) this lesion would have been visible. This, plus her reported symptoms would have saved her a six month wait and possibly caught her disease earlier.</i></p>
<p>at this point (6 months since I had initially presented at the GP with concerns), the waiting list for routine Colposcopy had increased weeks, so I was referred urgently for a colposcopy appointment and was seen within two weeks of the GUM appointment.</p> <p>At the colposcopy it was confirmed that my symptoms aligned those of cervical cancer and the cells needed to be removed tested. Here I had the LLETZ procedure and awaited the waiting 4 weeks for my results to be returned.</p> <p>I attended the colposcopy clinic to receive my results and the cells were found to be pre-cancerous CIN3 cells (the stage before it can potentially become cancerous). I felt relieved, but had a few questions unanswered.</p>	<p><i>She's angry, you can hear it. A 6 month wait. Rising anxiety – more waiting. Relief at being referred, being seen, being heard Worry at urgency? Relief</i></p> <p><i>'Aligned with' – very detached way of phrasing it – distancing herself? Use of terminology – researched this, it wasn't used before. More waiting. Agonizing – emotive terms. It was painful. Phoned to chase – active? Anxious? Trying to minimise the wait/make it mean something. Minimise the liminality? 'Pre-cancerous CIN3 cells' – not my cells – detachment?</i></p>	<p><i>6 months could have been the difference between CIN3 and cancer. Once you have been labelled a cancer patient your life insurance goes through the roof, you're not getting a mortgage and employers might be reluctant to take you if you explain the gap in your CV as 'I was having cancer treatment'. Any Colposcopy department with a twelve week wait is failing their key performance standard of seeing everyone in 6 weeks.</i></p> <p><i>'Aligned with cervical cancer' – I suspect this is a quote from the colposcopist/gynaecologist – it's a very circumspect, very careful way of putting it – this could be a form of care – it's gentler than saying 'suspicious of' or 'likely to be'. Having been told her (long!) history of attempting to seek treatment, s/he was possibly trying not to drop the GP in it for the</i></p>

<p>at this point that I sought advice from the online ask a professional service offered by 'Jo's cervical cancer trust'. I came across the website from my own online searches and seen a poster displayed at the hospital. I was bemused at how I had presented with cervical cancer symptoms, yet not yet diagnosed cancerous cell growth, and I equally was concerned about finding the cause.</p> <p>It was the most valuable information I received throughout my experience. My questions were answered thoroughly and it was here that I realised the likelihood of my cell change was a result of having had HPV.</p>	<p>Mentions of stages of CIN, and knows the difference between cancer and pre-cancer – has done some serious reading.</p> <p>Relief, but then more questions – what were they? Concerns? Anger? Did she voice the questions or did she not feel able to?</p> <p>'My own online searches' – ownership of condition/information.</p> <p>Bemused – light-hearted term? Not confused/bewildered. Past tense. Talks about cancerous cells as if they are different to her own cells. Non-self.</p> <p>How did this happen to me?</p> <p>'How'/'why' – most valuable. Online info exchange valuable. Thoroughly – time to process, time to think</p> <p>'My cell change' – after treatment it's hers again, or accepting responsibility</p> <p>'having had HPV' – past tense.</p> <p>Covering/passing (to me?)</p> <p>'I did, but I don't now'? Or, 'I didn't know I had it'?</p>	<p>delayed referral whilst providing as much accurate information as possible.</p> <p>As a practitioner, I take this knowledge for granted.</p>
<p>...this created more questions as I had received my course of injections at 13/14 years of age, was a non-smoker with a healthy lifestyle, had not had sexual intercourse at a young age and had a very low number of sexual partners. It seemed that I had been unlucky- and gone against the risk factors and statistics. I was informed that I must have had a very high risk type of HPV but not yet immunised against, and that my immune system</p>	<p>Aware of stigma/attribution – I did everything right.</p> <p>Justification.</p> <p>Ill-luck/fortune</p> <p>Follow up on this – how did she feel about having</p>	<p>13/14years, and she's 22. So born in 1995 ish.</p> <p>= Part of the catch-up as vaccine was implemented in 2008 and administered at age 12</p> <p>Correct. Current vaccine protects against two strains responsible for 70% of CaCx in the UK. Check no. of</p>

<p>not strong enough to fight the virus- thus causing cells to begin.</p> <p>Following my LLETZ treatment, my wound was not healing as it should and I had to return to the hospital twice more. I had some treatment to address this and a biopsy was taken, which came back clear.</p> <p>When I had CIN3, I was now entitled to have a smear test three months following this last treatment as a 'test of cure'. My luck held, and the result for this returned negative for both abnormal cells and HPV. This was the best outcome I could have hoped for. Somehow, my immune system had managed to fight HPV and thus no abnormal changes had occurred, by this point it had been just over a year since my initial visit to the GP; although I at times felt a little resentful that the process was so drawn out because of my age and the guidelines, I also felt extremely relieved and had a sense of closure from the ordeal.</p>	<p>an immunisation that didn't work.</p> <p>Not healing – more anxiety More visits = more invasion, more disruption Biopsy result barely mentioned – used to it by now?</p> <p>She sees this as lucky. Wow.</p> <p>Reassurance. Active response, not passive healing.</p> <p>Waiting. Recall – a year of disruptions.</p> <p>'Because of my age' – justifying the wait because her case was not the norm? Lucky not to have had cancer? Lucky not to have died? Lucky to retain fertility? She mentioned unlucky earlier. Confusion? Closure. Ordeal (not journey/experience) – pain, fear, anxiety. For a year.</p>	<p>doses given so far, and extrapolate number of girls vaccinated but still vulnerable.</p> <p>Correct procedure is a follow up TOC at six months. Earlier than this (especially where there have been complications) and there is a risk of a false positive HPV test of cure, or reparatory debris affecting sample quality = more treatment, more invasion.</p> <p>The process was drawn out because the GP didn't refer her straight away.</p>
<p>Through my own online research and my contact with Jo's cervical cancer trust I understand that it is not yet known whether my body has completely eradicated HPV, or whether it will lie dormant dependent on the strength of my immune system to fight it off. As a result, I will never take good health for granted. Most days anything triggers my thoughts to return to how lucky I have been. I continue to feel frustrated by the guidelines that are in place, and I think of the possible outcome had I not persisted to have the</p>	<p>Uncertainty. Possibility of a lifetime of infections.</p> <p>This is gratitude, but also a massive burden. Emotional/outlook positivity. BUT... intrusive thoughts? What are her triggers? How to live with this?</p>	<p>Dormancy/latency is still an issue. If she tests HPV negative in the future is it because she has cleared it, or because it is dormant. If she tests positive in the future is it the same virus reactivating, or a new infection with a different strain – we don't know yet.</p>

<p>...oms and concern addressed. ...is reason, I think patient information and education ...unding HPV, smear tests and cell changes is vital.</p> <p>...e this experience I knew little about HPV- just that I had had ...vaccinations for it, and recalled the campaign surrounding Goody. Now I feel much more informed through my own ...research and ensuring I ask appropriate questions at ...al appointments.</p> <p>...ver, it has highlighted that further research appears to be ...ed around HPV- and I feel information provision could have ...d inform me better from an earlier stage. I will always ...er about the origin of how I contracted it and feel concern for ...g potentially passed it on to my partner.</p>	<p><i>Blame? Blame of the system?</i> <i>Dread – of what could have been.</i> <i>Persistence – take back power, over body, over healthcare relationship.</i> <i>Information and education - empowerment</i></p> <p><i>Lack of knowledge</i></p> <p><i>Self taught. Empowered.</i> <i>Expectations of health professionals</i> <i>Further research - failed by lack of knowledge by health professionals?</i></p> <p><i>How did I get this – blame?</i> <i>Transmission.</i></p>	<p><i>'Just that I had had some vaccinations for it' – HPV awareness campaign not effective in her case then, and negates the idea of disinhibition following vaccination.</i> <i>'Jade Goody' – died the year after vaccination was implemented.</i></p>
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**Appendix 12: Jo's Narrative**

Question/prompt Response/Narrative	Researcher Interpretation	Practitioner Interpretation
<p>Tell me a little bit about yourself Basically I'm a student adult nurse. I'm nearing the end of my training and am currently in the process of selecting my choices of roles at (name of institution redacted). I am really interested in getting into gynaecology and I'm hoping that my selections will help me get there.</p>	<p>Health literate  ?Hopes to use experience to help her practice</p>	<p>Health literate</p>
<p>Can you tell me about your diagnosis? To cut a long story short I suffered a miscarriage in Feb 2016 and the smears ever since have come back as pre-cancerous and I believe it was the management of the miscarriage that contributed to this. I received the all clear (as far as not needing further colposcopy treatment ) in May and have just got to have another check up at the hospital Colposcopy clinic next May.  So when I found out about the HPV positive I was shocked but was also aware that it is extremely common. I felt a little embarrassed but I think that's fairly normal. The only thing about the treatment process which could have been better was the letter to inform me of my colposcopy appointment. It was worded as if it was inevitable that I'd require</p>	<p>Miscarriage is a massive life event. Disruption? Pre-cancerous (vs. cancerous) = she knows the difference. Terminology Senselessness of miscarriage (Neimeyer 2000) – individuals driven to find meaning. Has this translated to her experience of CIN/HPV? Meaning making – sense making vs. benefit finding? A wait of 12 months, but doesn't mention this as difficult HPV positive. Shock. Doesn't mention anxiety etc. Awareness of ubiquity = less stigma? Embarrassment, then rationalisation. No mention of partner or whether she disclosed.  She mentions no need for treatment, but then later mentions she definitely had it. Does she mean again ('further treatment'). Wording of communications.</p>	<p>My response to this as a practitioner is confusion. Does she mean that, say, curettage caused injury to her cervix that left her vulnerable to HPV infection? Theoretically possible. Research it. 'Smears ever since' – indicates more than one? Miscarriage is treated the same as delivery – she would have had to wait three months after miscarriage to have a smear = May 2016 earliest? There is no repeat in 6 months any more, so that one smear would have had to be her referring (abnormal) smear. She had treatment, so she must have had a TOC... and recall to Colposcopy 12 months post treatment indicates that she was HPV positive post-treatment. All clear in May 2017, less 1 month to refer back to colp = Six month follow up in Apr 2017. Less the six months post treatment...</p>

<p><i>further treatment but this was not the case. Would have been better if the letter was clear about the fact that further loop diathermy may not be needed as I had planned for recovery time and someone to take me so I didn't have to drive afterwards. Also think that information about HPV should be included in correspondence so that the patient is more informed. There are a lot of forums out there which are not always effective and can be misconstrued. The Jo's Cancer Trust [sic] website is informative but having the word 'cancer' all over the pages is very daunting and scary.</i></p>	<p><i>Terminology again – health literacy (?due to training rather than research?) Mobilisation of resources/physical support (drivers etc.) More information on HPV Patient should be more informed Lots of access to info. Quality of information not always guaranteed. Cancer – fear when not required?</i></p>	<p><i>= treated in October 2016. Less one month for referral = HPV positive/referring smear probably September 2016 So between May 2016 (earliest) and Sep 2016 (latest) Practice point: NHSCSP result letters are standardised. Hospital/gynae/colp letters are not – should they be – quality of info and care should be the same across the nation. Would save time and money. Jo's trust is evidence based/peer reviewed, so info would be good.</i></p>
<p>Meaning making – feelings surrounding diagnosis/diagnostic process Can you describe how you felt after you were diagnosed?</p> <p><i>Worried. Just one thing after another.</i></p> <p>Can you tell me how you came to your diagnosis (letter/face to face appointment). <i>Found out by letter</i></p> <p>Can you tell me what stages were involved in the diagnostic process?</p> <p><i>Tissue sent off taken from loop diathermy</i></p>	<p><i>Anxiety. 'One thing after another' – reference to miscarriage?</i></p> <p><i>No opportunity to ask questions.</i></p> <p><i>Definitely had treatment then, but doesn't say how many appointments she had.</i></p>	<p><i>Patients have the opportunity to ask questions, but this is when you are gowned up and on the table...</i></p> <p><i>A 'See and Treat' appointment means they saw a high grade lesion on Colp right from the get-go. If she had had a biopsy first, it means they saw a low grade lesion that came back high grade.</i></p>



<p>Can you tell me what you thought about HPV before your diagnosis? How does it differ from your thoughts now?</p> <p><i>I thought it was very common for those whom had several sexual partners, personally this was not the case for me.</i></p>	<p><i>Assumptions about ‘women who get HPV’ – see Nack 2002, 2000. ‘Good girls/Fallen women’? “I am not like that”? Can happen to anyone?</i></p>	
<p>Can you tell me what your diagnosis means to you?</p> <p><i>Heightened awareness</i></p> <p>If you could go back – what advice would you give to yourself about hearing the news for the first time?</p> <p><i>To not worry as is completely normal.[sic]</i></p>	<p><i>More aware of what? HPV? Her gynaecological/reproductive health? Her overall health?</i></p> <p><i>Learned from her experience that ‘it is very common’ – see earlier comment</i></p>	
<p>Biographical work – the self</p> <p>How would you describe yourself as a person?</p> <p><i>Informed. Anxious. Kind. Caring.</i></p> <p>Has your outlook changed since your diagnosis?</p> <p><i>Outlook yes, as I feel I will be a better nurse having these personal experiences. ‘Roles’: No. (Jo also mentions that the way she sees/thinks</i></p>	<p><i>Informed via health literacy/training? Anxious in general or due to condition/events?</i></p> <p><i>Interesting that both individuals who were healthcare professionals mention that they will use this experience to improve their practice.</i></p>	

<p><i>about herself has not changed since her diagnosis.)</i></p> <p>Overall, has this been a positive or a negative experience in your life.  <i>Positive in terms of my professional career.</i></p>	<p><i>No reference to her private life or feelings/emotions. Compartmentalising?</i></p>	
<p>Daily Life</p> <p>Can you describe a typical day?</p> <p><i>Student nurse, so can be exams, reports or on placements.</i></p> <p><i>(Jo also notes that she doesn't plan her days around how she is feeling)</i></p> <p>Can you tell me about a good day, and a bad day?  <i>Good day – spent with daughter</i>  <i>Bad day – filled with anxiety</i></p>	<p><i>Again, doesn't mention her personal life - ?interviewer effect – she doesn't know me. I can't prompt.</i></p> <p><i>Should have made the questioning for this more clear.</i></p> <p><i>Again, should have been clearer</i>  <i>Family.</i>  <i>Anxiety – over HPV? Recurrence? Fertility?</i>  <i>Mortality? Career/deadlines?</i></p>	

<p>Support</p> <p>Do you post online, or do you just read?  Can you tell me why you 'just read'?  (if you just read)  Can you tell me about your first online post?</p> <p><i>I posted online re cervical screening and feel very lucky and passionate about it. I haven't posted directly about HPV</i></p> <p>How do you feel after conversations about your experiences?  <i>Open, honest, positive.</i></p> <p>How do you feel after a forum visit?  <i>Confused as people have such different experiences. (Jo also mentioned she felt positive after she had posted)</i></p> <p>Do you feel you get different information or support from a particular group – say your physical friends vs online individuals  <i>Yes, support from my nursing friends is more evidence based.</i></p>		
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or I thought it was very common for those whom had several sexual partners. Personally this was not the case for me.

THEME TO EXPLORE	TYPE OF QUESTION						
	DESCRIPTIVE	NARRATIVE	STRUCTURAL	CONTRAST	EVALUATIVE	CIRCULAR	COMPARATIVE
Meaning making: Feelings surrounding diagnosis/diagnostic process	Can you describe how you felt after you were diagnosed  - worried - just one thing after another	Can you tell me how you came to your diagnosis (letter/face to face appointment) found out by letter	So what stages were involved in the diagnostic or treatment process  issues sent off taken from loop - biathemy	Can you tell me what you thought about HPV before your diagnosis? How does it differ from your thoughts now? *	Can you tell me what your diagnosis means to you?  heightened awareness	If you could go back - what advice would you give to yourself about hearing the news for the first time? To not worry as it's completely normal	
Biographical work - The Self	How would you describe yourself as a person?  - informed - anxious - kind - caring	outlook yes as feel I will be a better nurse having these personal experiences. 'role' no.	Has your outlook or your role changed since your diagnosis?	Has your diagnosis changed the way you think about yourself?  NO	Do you feel you are a different person - since diagnosis/ since getting the all-clear? No.	Overall, has this been a positive or a negative experience in your life?  positive in terms of my professional career.	
Daily Life	Can you describe a typical day? Student nurse so can be exams, reports or on placement		Do you plan days or events around how you are feeling?  normally -	Can you tell me about a good day, and a bad day?	Good day - spent with daughter Bad day - filled with anxiety		
Support	Can you tell me about a time when HPV came up in conversation with a partner/friend/family member? Do you post online, or do you just read - can you explain why you just read? Can you tell me about your first online post?		What was the process of getting involved with online support?  How did you become an advisor/administrator?  Do you plan posts or questions in advance, or do you respond to what you see/read?		How do you feel after conversations about your experiences?  How do you feel after forum visit?  How do you feel after you've posted	} open, honest } positive  - confused as people have such different procedures & experiences.  - positive	Do you feel you get different information or support from a particular group, say, your physical friends or your online friends?  yes, support from nursing friends more evidence based.